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CHARTBOOK ON WOMEN AND DISABILITY IN THE UNITED STATES

National Institute on Disability
and Rehabilitation Research

Chartbook on Women and Disability in the United States

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Foreword

The National Institute on Disability and Rehabilitation Research (NIDRR) is committed to maximizing opportunities for all people with disabilities and to expanding national understanding of disability issues. In conjunction with this mission, NIDRR is pleased to publish this **Chartbook on Women and Disability in the United States**.

This book is a rich resource for anyone interested in disability and its impact on girls and women. The chartbook is one in a series of publications funded by NIDRR and produced by the InfoUse Center on Improving Access to Disability Data. The InfoUse Center makes available statistical information on disability, both in print and on the World Wide Web. Data is presented in an easy-to-read format, useful for people with different educational levels, technical skills, sensory disabilities, and cognitive capabilities. The chartbook is useful for people with disabilities, policymakers, advocates, planners, researchers, rehabilitation and health care professionals, and others interested in disability data and women.

In order to expand opportunities for the full participation of girls and women with disabilities in society, it is essential to understand the nature of that participation. The new paradigm of disability emphasizes the person with a disability acting in the environment and dealing with various opportunities and barriers in making life choices and achieving individual goals. The **Chartbook on Women and Disability in the United States** describes the current status of women with disabilities, relative to other women and men with and without disabilities, in a number of different aspects of life. By identifying the specific barriers and discrimination faced by girls and women, the chartbook paves the way for policy and attitudinal changes to ensure equal opportunity. The chartbook also highlights gaps in the research on both disability and gender. Hopefully, this information will stimulate further thoughtful discourse and the creation of policy innovations that will provide more and better opportunities for girls and women with disabilities.

Katherine D. Seelman, Ph.D., Director
National Institute on Disability and Rehabilitation Research

Acknowledgments

The **Chartbook on Women and Disability in the United States** relies on published data from many federal agencies and organizations. We are very grateful to all of the people and agencies responsible for collecting, maintaining, and analyzing these data. The following people graciously assisted us by providing current information, reviewing our text and graphics, and providing ideas for making the chartbook more accessible to blind and visually impaired people.

- Carol D'Onofrio, Breast Health Access for Women with Disabilities and Northern California Cancer Center
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- Barbara Wenger, Disability Statistics Research and Training Center

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This chartbook is a product of the InfoUse Center on Improving Access to Disability Data, a program supported by a grant by the National Institute on Disability and Rehabilitation Research (H133D50017-96). This is one of a series of products and activities intended to make information on disability and on disability statistics available to wider audiences.

Preface

The **Chartbook on Women and Disability in the United States** is a reference on women and disability in the United States population, created for use by both non-technical and technical audiences. The book is a resource for agencies, employers, organizations, policymakers, researchers and others concerned with the relationship between gender and disability.

Each section addresses an aspect of women and disability. Each page within the section contains a topic question, explanatory text on the topic and an explanatory graphic or table that provides data in an easy to read form. The figure title gives the name of the graphic and provides a reference to a corresponding data table at the back of the chartbook. The source of the information and the survey used to collect the data appear at the bottom of the page. In many cases, we also include information on relevant website addresses on the World Wide Web, where more detailed information may be stored. The key surveys, shown in **boldface** when mentioned in the text, have a technical summary that is located in the Appendix. In the text, key terms are also shown in **boldface** and are defined in the Glossary.

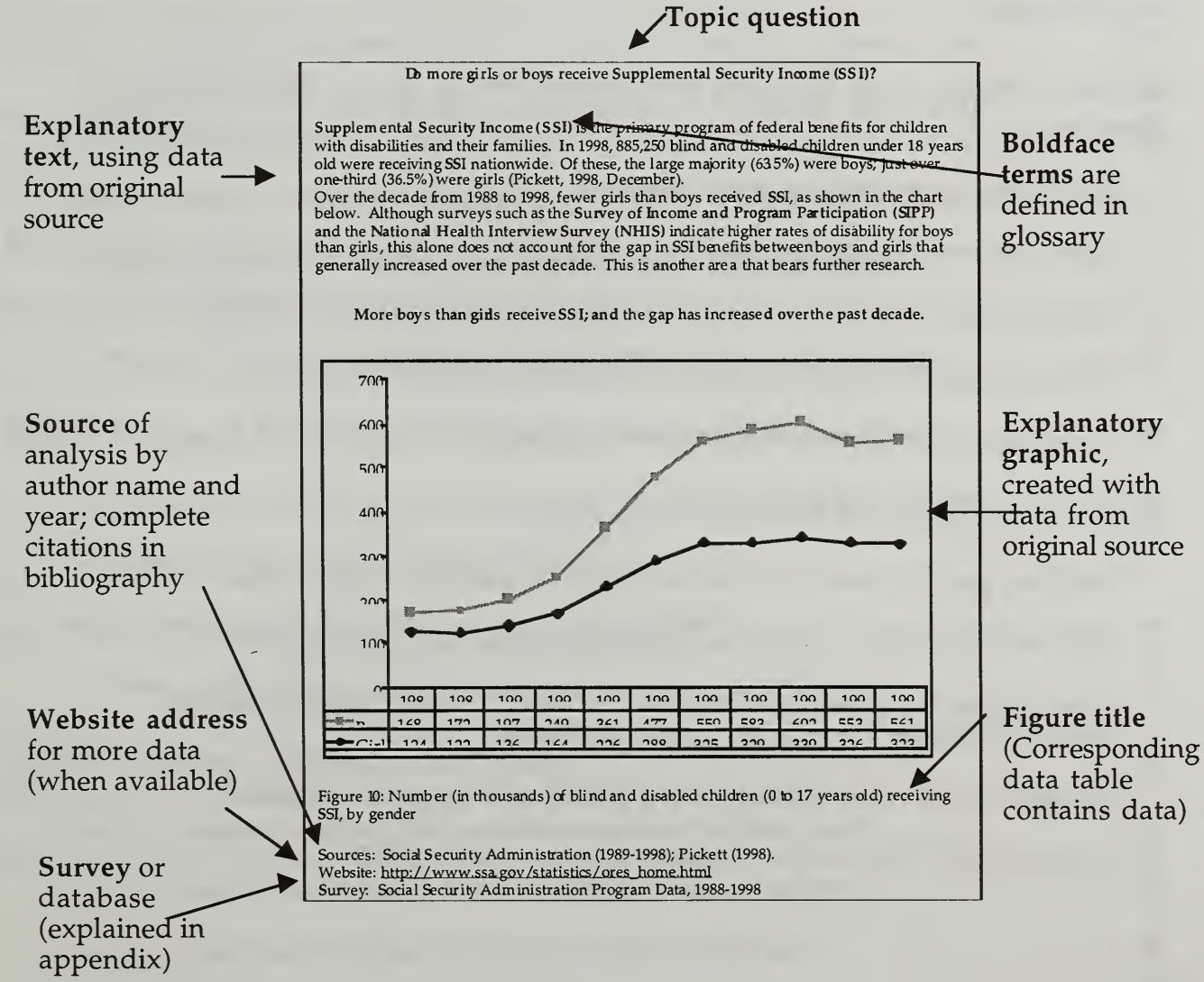

Topic question
Do more girls or boys receive Supplemental Security Income (SSI)?
Supplemental Security Income (SSI) is the primary program of federal benefits for children with disabilities and their families. In 1998, 885,250 blind and disabled children under 18 years old were receiving SSI nationwide. Of these, the large majority (63.5%) were boys, just over one-third (36.5%) were girls (Pickett, 1998, December).
Over the decade from 1988 to 1998, fewer girls than boys received SSI, as shown in the chart below. Although surveys such as the Survey of Income and Program Participation (SIPP) and the National Health Interview Survey (NHIS) indicate higher rates of disability for boys than girls, this alone does not account for the gap in SSI benefits between boys and girls that generally increased over the past decade. This is another area that bears further research.
More boys than girls receive SSI; and the gap has increased over the past decade.
Figure 10: Number (in thousands) of blind and disabled children (0 to 17 years old) receiving SSI, by gender
Sources: Social Security Administration (1989-1998); Pickett (1998).
Website: http://www.ssa.gov/statistics/ores_home.html
Survey: Social Security Administration Program Data, 1988-1998
Explanatory text, using data from original source
Boldface terms are defined in glossary
Source of analysis by author name and year; complete citations in bibliography
Explanatory graphic, created with data from original source
Website address for more data (when available)
Figure title (Corresponding data table contains data)
Survey or database (explained in appendix)

Table of Contents

Foreword iii

Acknowledgments iv

Preface v

Table of Contents vi

List of Figures ix

List of Tables xi

Introduction 1

Section 1: Women and disability throughout the life cycle: Definitions and prevalence 3

How many women and men have a disability? 4

How does activity limitation differ by gender? 5

Are the activity limitations of women and men caused by different conditions? 6

What are threats to health and safety for females, compared to males? 7

Do women's disability rates differ by race and ethnicity? 9

Section 2: Children and youth with disability 11

Are there gender differences in the prevalence of disability among children? 12

What are the conditions that cause activity limitations in girls and boys? 13

Over the past two decades, has enrollment in federally funded special education changed in relation to total public school enrollment? 14

Do girls and boys have different rates of participation in special education? 15

Do more girls or boys receive Supplemental Security Income (SSI)? 16

Section 3: Women: Disability, work, income and benefits 17

How often do women with disabilities have a job or business? 18

In which occupational categories are women with disabilities employed? 19

How often are women with disabilities employed in computer-related jobs? 21

Does labor force participation of people with a work disability differ by gender? 22

How do median earnings for women with and without disability compare to men's earnings? 23

How many women with a work disability are living in poverty? 24

Do women and men with a work disability differ in benefits they receive? 25

Are there gender differences in Social Security benefits for disabled workers? 26

Are there gender differences in people served by Vocational Rehabilitation? 27

Section 4: Living arrangements, family life, and medical experiences 29

Are there differences in marital status among women and men with and without activity limitations? 30

What percentage of women and men with and without disability are parents? 31

Do medical expenditures differ among women and men with and without activity limitations? 33

Do women with functional limitations receive appropriate cancer screening? 34

Section 5: Mental disorders and disability: Gender differences 35

Are women more likely than men to experience a mental or psychiatric disorder? 36

Do women use more mental health services than men? 37

What is the extent of disability due to mental disorders? 38

Are there gender differences in limitations due to serious mental illness? 39

Section 6: Women, disability and aging 41

How do changes in women's life expectancies impact disability rates? 42

How does the need for personal assistance differ by age and gender? 44

How do age and gender influence the rate of multiple conditions? 45

What is the impact of arthritis on women? 47

How many women are at risk of disability related to osteoporosis? 48

Do women and men have different rates of independent living as they age? 49

Who provides care for elderly people with disabilities? 50

Section 7: Research Gaps and Topics for Further Investigation 51

Data Tables 55

Glossary 67

Bibliography 77

Website Addresses 84

Appendix 87

List of Figures

Figure 1: Americans with and without disability, by gender 4

Figure 2: Percentage with activity limitation, by age group and gender 5

Figure 3: Injury rate per 100 population, by gender, 1983-1993 7

Figure 4: Number of disability days lost annually per person, by gender 8

Figure 5: Percentage with disability, by gender and ethnicity 9

Figure 6: Disability rates for children and youth (0 to 21 years old) by age group and gender 12

Figure 7: Activity-limiting main conditions with highest prevalence for children under 18, by gender 13

Figure 8: Children and youth (0 to 21 years old) in special education, as percentage of total public school enrollment, by disability type, 1977-1995 14

Figure 9: Percentage enrolled in special education, by gender and disability type 15

Figure 10: Number (in thousands) of blind and disabled children (0 to 17 years old) receiving SSI, by gender 16

Figure 11: Percentage with job or business, by disability status and gender, 21 to 64 years old 18

Figure 12: Number and percentage of people with and without disabilities in computer-related job categories, by gender, 16 to 64 years old 21

Figure 13: Percentage participating in labor force, by work disability status and gender, 16 to 64 years old 22

Figure 14: Median monthly earnings, by disability status and gender, 21 to 64 years old 23

Figure 15: Percentage of people living below poverty level, by work disability status and gender, 16 to 64 years old 24

Figure 16: Percentage of people with work disability participating in assistance programs, by gender 25

Figure 17: Average monthly Social Security benefit for disabled workers, by gender, in five-year increments, 1960-95 26

Figure 18: Number of Vocational Rehabilitation cases closed, by type of closure and gender 27

Figure 19: Marital status, by activity limitation status and gender, 18 and older 30

Figure 20: Percentage of adults with children under 18 years old in home, by disability status and gender 31

Figure 21: Per capita medical expenditures, by age group, activity limitation status, and gender ... 33

Figure 22: Lifetime prevalence of certain types of psychiatric disorders, by gender 36

Figure 23: Percentage of people with mental disorders who sought treatment, by gender and type of mental health provider 37

Figure 24: Percentage of people with severe mental illness reporting limitations in aspects of daily functioning, by gender 40

Figure 25: Percentage of women and men who were 50 years old in 1900, 1950, and 1990, who can expect to live to the age of 90 42

Figure 26: Percentage of people needing personal assistance with ADLs or IADLs, by age group and gender 44

Figure 27: Percentage of those with chronic conditions who have more than one condition, by age group 45

Figure 28: Percentage of people with more than one chronic condition, by gender 46

Figure 29: Age-adjusted prevalence and activity limitation due to arthritis, by gender 47

Figure 30: Percentage of women over 50 with osteoporosis, by age group 48

Figure 31: Living arrangement status of women and men 65 years and older, by age group 49

Figure 32: Gender of people who provide care to older people with chronic health conditions 50

List of Tables

Table 1: Activity-limiting main conditions with highest prevalence, by gender..... 6

Table 2: Number and percentage of people with disabilities in major occupational categories, by gender, 16 to 64 years old.....20

Table 3: Characteristics of parents with disability, parents with no disability and adults with disability who are not parents.....32

Table 4: Percentage of women who received Pap test (past 3 years), by age group & functional limitation status (FLs).....34

Table 5: Percentage of women who received mammogram, by age & FLs.....34

Table 6: Prevalence of disability among those with mental disorders.....38

Table 7: Growth and estimated growth of the older population in the United States, 1940-2040.....43

Introduction

Disability impacts women at all ages, across the entire life course. Girls and women with disabilities encounter a variety of barriers at different points in their lives. Young girls may need special programs to make education and future career opportunities accessible to them. Working-age women face barriers to entering and participating in the workforce. Inaccessible work environments, low wages, and lack of jobs leave many women with disabilities reliant on public benefits and living in poverty. Adult women with disabilities also encounter barriers to participating fully in other aspects of life, including obstacles to parenting, and lack of access to medical care. Elderly women with disabilities are a rapidly growing group, and often require distinct forms of assistance, equipment, or services in order to live independently. The chartbook examines these issues, comparing the demographics and experiences of women with disabilities to those of other women and men with and without disabilities.

Data included in the **Chartbook on Women and Disability in the United States** are derived from national surveys such as the **Survey of Income and Program Participation (SIPP)**, the **National Health Interview Survey (NHIS),** including the **1994-95 Survey on Disability**, the **Current Population Survey (CPS)**, and the **Decennial Census ("the Census")**. In addition, other analyses by federal agencies such as the Social Security Administration, the Rehabilitation Services Administration and others are summarized. In some areas of investigation, comprehensive national data sources are not available and smaller or more specialized surveys and databases are utilized.

The chartbook is organized in seven major sections: **Section 1** introduces the topic of women and disability throughout the life cycle, providing an overview of gender and disability across the life span. **Section 2** focuses on children and youth with disability, including prevalence, conditions, educational programs and certain benefits. **Section 3** examines the complex issues of women with disabilities and work, including labor force participation, earnings and benefits. **Section 4** covers the broad topics of family life and living arrangements, as well as certain medical experiences of women with disabilities. **Section 5** reviews differences between women and men in terms of disability due to mental illness, including prevalence of mental conditions, utilization of mental health services, and limitations caused by mental illness. **Section 6** discusses the disability-related effects of aging on women, including the much higher rates of disability and multiple conditions and changing personal assistance needs. Caregiving, another women's issue related to aging and disability, is also discussed. **Section 7** presents gaps in the research on women and disabilities that need further attention and research.

Section 1: Women and disability throughout the life cycle: Definitions and prevalence

First, this chartbook presents an overview of disability **prevalence** among women. Prevalence is the number of cases with a given attribute that are present during a particular interval of time, often expressed as a rate or percentage. Discussion of disability prevalence must be prefaced with a description of the major national surveys and their disability definitions. Federal surveys, by sampling large numbers of people, make it possible to estimate the prevalence and describe certain characteristics of women with disabilities on a national, summary level. However, the questions asked on these surveys also limit the characteristics and experiences of women with disabilities that can be described.

The best national estimates of disability come from the **Survey of Income Participation (SIPP)** and **the National Health Interview Survey (NHIS)**, including the **NHIS Survey on Disability (NHIS-D)**. Each survey defines disability somewhat differently and the surveys all tend to under-report stigmatized conditions such as mental illness. Section 1 opens with a description of the disability definitions used in these surveys, and presents recent estimates of how many women and men have disabilities.

Section 1 also introduces information on the causes of disability for women and men, respectively. The impact of demographic factors such as age and ethnicity on women's disabilities are also discussed in this section.

Topic Questions:

How many women and men have a disability?

How does activity limitation differ by gender?

Are the activity limitations of women and men caused by different conditions?

What are the threats to health and safety for females, compared to males?

Do women's disability rates differ by race and ethnicity?

How many women and men have a disability?

The **Survey of Income and Program Participation (SIPP)** uses a broad-based definition of **disability**. The SIPP definition considers limitations in specific **functional activities, activities of daily living (ADLs)**, and **instrumental activities of daily living (IADLs)**, as well as the use of special aids, the presence of certain conditions related to mental functioning, and questions pertaining to the ability to work. According to the SIPP, one in five Americans has a disability, and 53% of those with disabilities are female.

In 1995, an estimated 20.6% of **non-institutionalized** civilians (53.9 million people) met the criteria for disability as measured by the SIPP. Women and girls with disabilities are estimated to number 28.6 million, which is 21.3% of the female population. An estimated 25.3 million men and boys with disabilities make up 19.8% of the male population.

One in five Americans has a disability;
more than half of those with disabilities are female.

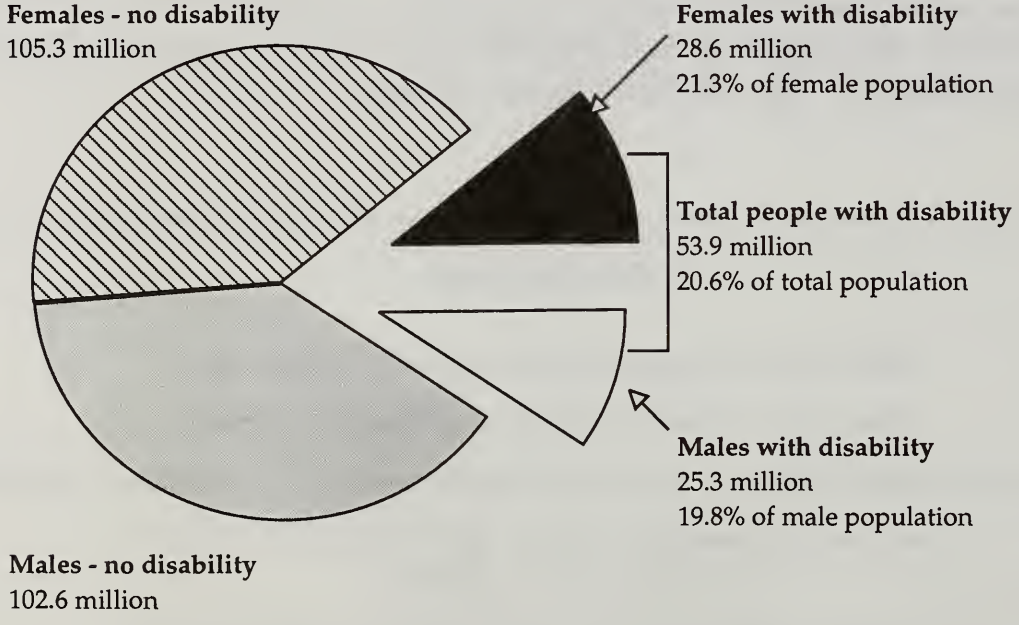


Figure 1: Americans with and without disability, by gender

Source: McNeil (1997). Website: http://www.census.gov/hhes/www/disable/sipp
Survey: SIPP, 1994-95

How does activity limitation differ by gender?

The **National Health Interview Survey (NHIS)** defines disability as a limitation in a **major activity,** caused by a **chronic health condition**. Major activities, defined in terms of age group, include: engaging in play for children under 5 years, attending school for children 5-17 years, working or keeping house for adults 18-69 years, and living independently for people 70 years and older. An **activity limitation** is a difficulty with or an inability to perform a major activity.

Overall, women have more activity limitations than men. Of the 129.3 million **non-institutionalized** females in the United States, 15.4% are limited in activity, compared to 14.6% of the 122.2 million males. However, women's higher rate of activity limitation is due to women's greater longevity and the fact that activity limitation increases sharply with age. Among people under 18 years old, only 6.1% have activity limitations (5% of girls; 7.1% of boys). In contrast, more than half of people over the age of 85 years experience activity limitations (59.3% of women; 50.2% of men). After statistically adjusting for age differences between men and women, women are no more likely than men to be limited in activity.

Females report more limitations in old age, while males report more limitations in youth.

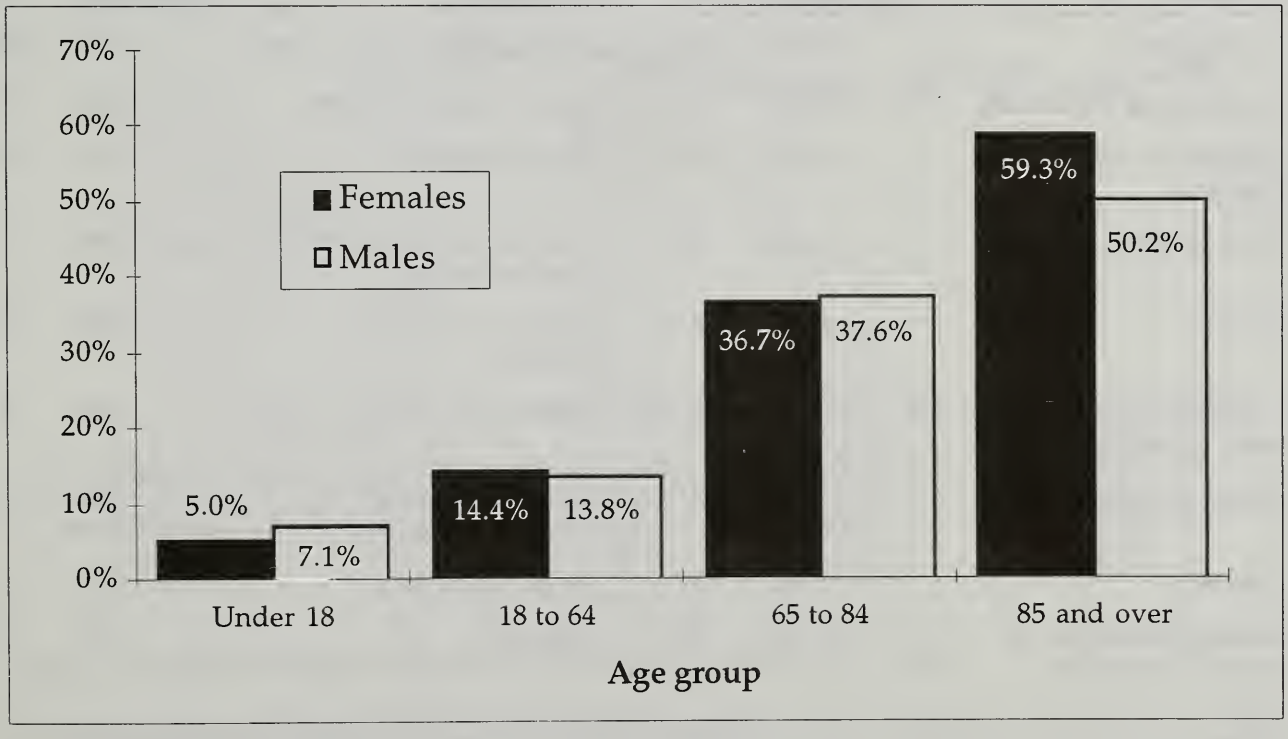


Figure 2: Percentage with activity limitation, by age group and gender

Source: LaPlante & Carlson (1996).
Survey: NHIS, 1992

Are the activity limitations of women and men caused by different conditions?

On average, women report a higher number of conditions causing **activity limitations** than men (1.67 versus 1.56 limiting conditions per person reporting the activity limitation). As shown in the table below, there are also gender differences in the conditions that males and females report as the main causes of their activity limitations. Both sexes report back disorders as the most prevalent main cause of **disability**. Arthritis ranks as the second highest main cause of disability for women, and arthritis is more than twice as prevalent for women as for men (13.3% versus 5.8%). For women, heart disease ranks third, followed by asthma and orthopedic impairments of the lower extremities. Learning disabilities and mental retardation are less frequent disabling conditions for females than for males.

Women are more than twice as likely to be disabled by arthritis; men and boys are twice as likely to be disabled by learning disabilities or mental retardation.

FEMALES			MALES		
Main condition causing limitation	**Number (in 1000s)**	**%**	**Main condition causing limitation**	**Number (in 1000s)**	**%**
All conditions	19,950	100.0	All conditions	17,783	100.0
Spine or back conditions	3,059	15.3	Spine or back conditions	2,829	15.9
Arthritis & allied disorders	2,660	13.3	Heart diseases	2,028	11.4
Heart diseases	1,943	9.7	Orthopedic impairment of lower extremity	1,086	6.1
Asthma	1,051	5.3	Arthritis & allied disorders	1,038	5.8
Orthopedic impairment of lower extremity	833	4.2	Asthma	964	5.4
Mental disorders	668	3.3	Learning disability & mental retardation	881	5.0
Diabetes	665	3.3	Mental disorders	825	4.6
Learning disability & mental retardation	507	2.5	Diabetes	524	2.9

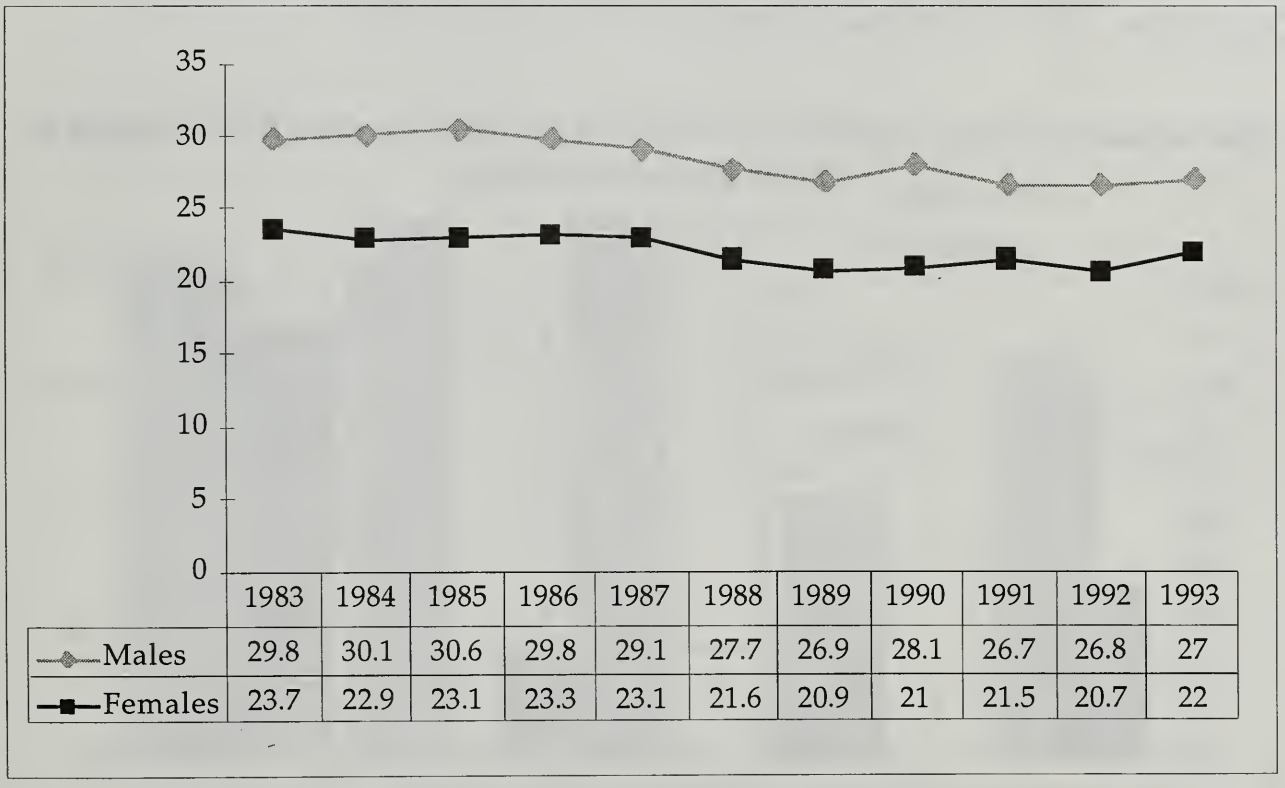
Table 1: Activity-limiting main conditions with highest prevalence, by gender

Source: LaPlante & Carlson (1996), Table M, p. 49.
Survey: NHIS, 1992

What are threats to health and safety for females, compared to males?

In general, women and girls are less likely to be injured than men and boys. The **National Hospital Discharge Survey** (1993-1994) revealed that females were less frequently hospitalized than males for internal injuries, sprains and strains, cranial injuries, wounds or lacerations. Females were more frequently hospitalized for poisoning and fractures than males (Fingerhut & Warner, 1997, p. 36). Another survey, however, found that females have overall lower rates of fractures than males (**National Health Interview Survey**, 1993: U.S. Bureau of the Census, 1997, Table 207, p. 38). The chart below shows the number of injuries (per 100 people in the population) that led to restricted activity and/or medical attention, as measured in the **NHIS**. Over the decade from 1983 to 1993, males were injured more often than females. At all ages, boys and men are more likely than girls and women to die from their injuries. (Continues on following page.)

Males consistently experience more injuries than females.



	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993
Males	29.8	30.1	30.6	29.8	29.1	27.7	26.9	28.1	26.7	26.8	27
Females	23.7	22.9	23.1	23.3	23.1	21.6	20.9	21	21.5	20.7	22

Figure 3: Injury rate per 100 population, by gender, 1983-1993

Source: U.S. Bureau of the Census (1995), Table 207, p. 137.
Survey: NHIS, multiple years

However, women and girls consistently report more days when illness or injury prevents them from productive activity. The chart below shows the number of days lost per person in 1994, by gender. It uses a number of different categories: **bed-disability days** (when a person stayed in bed for more than half a day), **work-loss days** (when a working person lost more than half a day of work) and **school-loss days** (when a child lost more than half a day of school). These measures are all higher for females than males. The summary measure, **restricted-activity days**, encompasses all of the above, as well as any other days when a person cut down on activities for more than half a day due to illness or injury. The rate for females (18.2 days per year) is substantially higher than the rate for males (13.6 days per year).

A number of factors may contribute to these differences. Women experience more non-fatal, chronic illness than men, while men's illnesses and injuries tend to be more life-threatening (Verbrugge, 1989). Other findings suggest that women experience more severe and frequent pain, and pain of longer duration than men. Women have also been found to engage in a greater repertoire of coping strategies to deal with pain and illness, perhaps restricting activity more readily than men, in order to heal (National Institutes of Health Pain Research Consortium, 1998, April; Unruh, 1996).

But women and girls experience more loss of productive days due to illness or injury than men or boys.

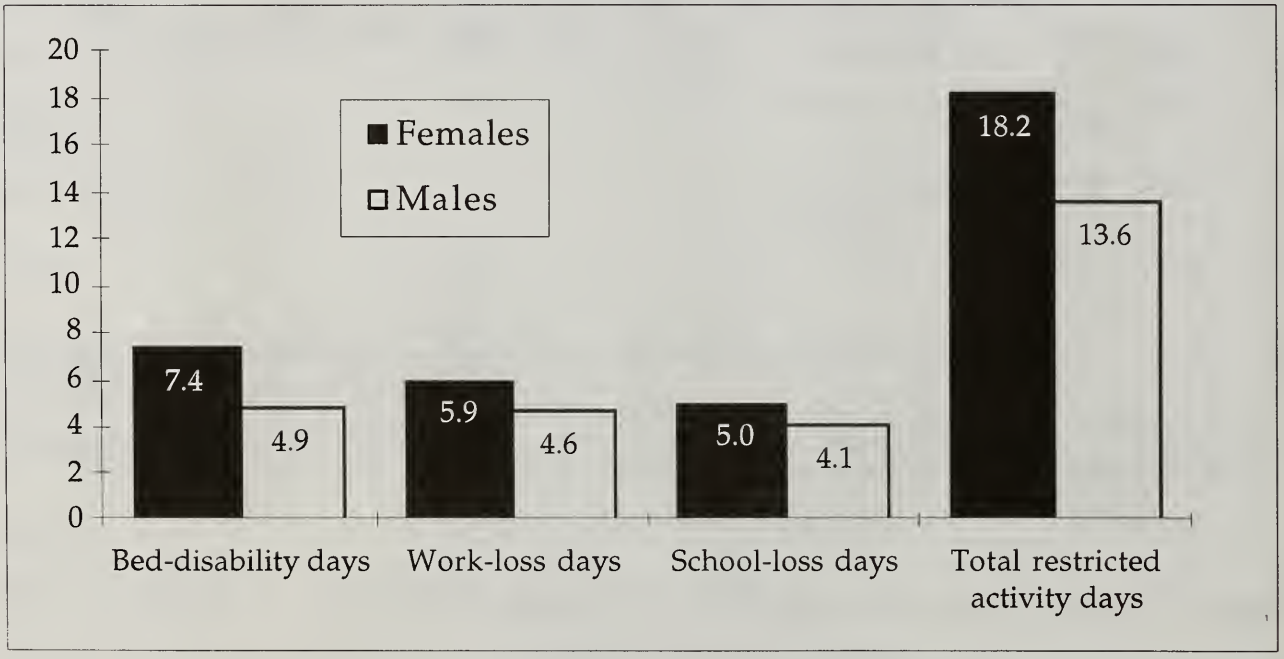


Figure 4: Number of disability days lost annually per person, by gender

Source: U.S. Bureau of the Census (1997), Table 206, p.138.
Survey: NHIS, 1994

Do women's disability rates differ by race and ethnicity?

In the general population, women have a higher rate of **disability** than men, due primarily to women's higher average longevity. According to the **Survey of Income and Program Participation** (1991-92), women have higher disability rates than men in all of the major ethnic and racial groups except Native Americans. Among females, Native Americans face the highest disability rate (21.8%), followed closely by Black females at 21.7%. White women have a disability rate of 20.3%, and the rate for Hispanic women is 16.2%. Among the female population, Asian/Pacific Islander women have the lowest disability rate of 10.7%.

These ethnic differences are probably due to a variety of factors including income, education and other socioeconomic disparities (LaPlante & Carlson, 1996), as well as possible cultural differences in how disability is experienced and reported. Further research is needed to investigate ethnic variability in disability rates, and to understand the experiences of ethnic minority women and girls.

Compared to other women, Native American and Black women have the highest rates of disability.

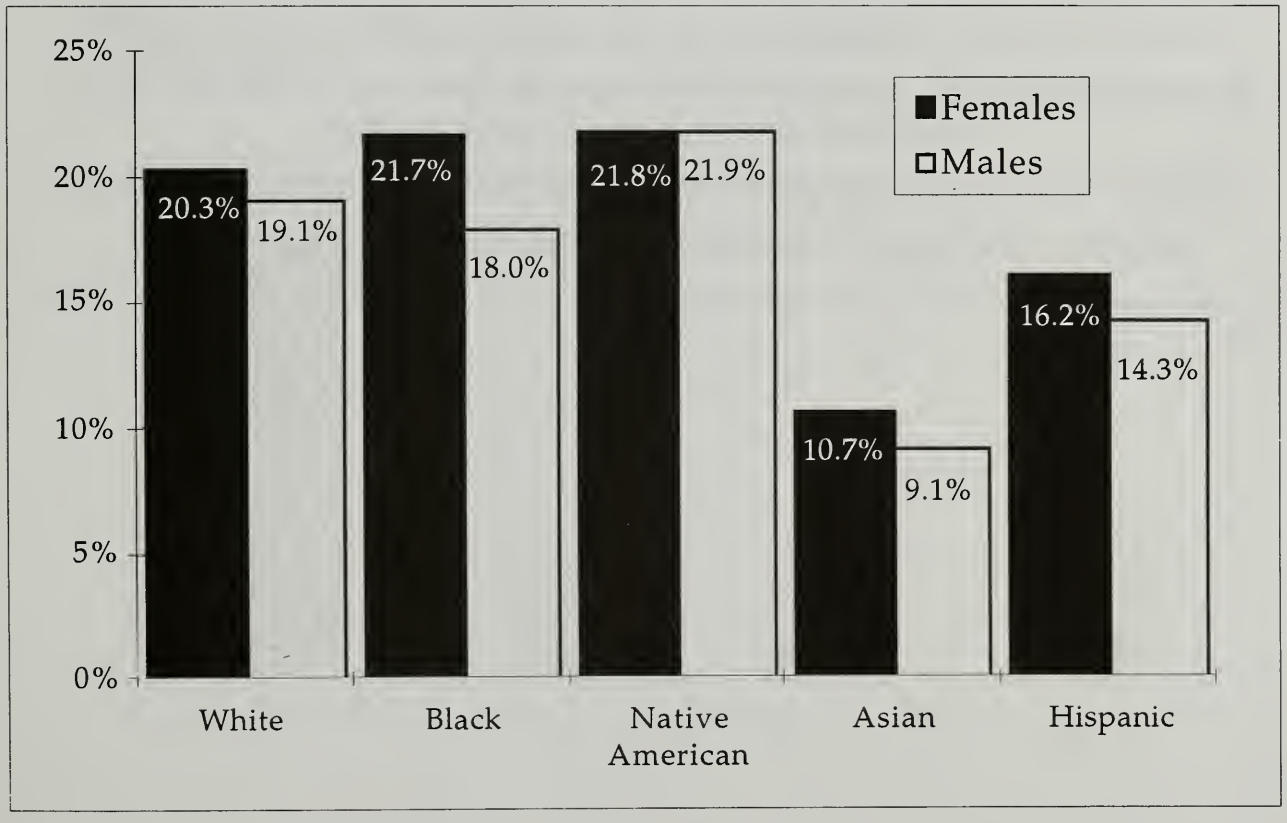


Figure 5: Percentage with disability, by gender and ethnicity

Source: Bradsher (1995); McNeil (1993).
Survey: SIPP, 1991-92

Section 2: Children and youth with disability

This section reports on the **prevalence** and causes of disability among children and youth. Section 2 also presents information on **special education** programs for girls and boys with disabilities. In addition, this section describes gender differences in rates of receiving **Supplemental Security Income (SSI)**.

A review of the literature reveals that relatively little has been written on gender differences among children with disabilities, or about the specific needs of girls with disabilities. More information is becoming available as researchers publish analyses of the **National Health Interview Survey on Disability (NHIS-D),** 1994-95, which included a number of specific questions about children with disabilities.

Topic Questions

Are there gender differences in the prevalence of disability among children?

What are the conditions that cause activity limitation in girls and boys?

Over the past two decades, has enrollment in special education changed in relation to total public school enrollment?

Do girls and boys have different rates of participation in special education?

Do more girls or boys receive Supplemental Security Income (SSI)?

Are there gender differences in the prevalence of disability among children?

According to the **Survey of Income and Program Participation (SIPP)** and other surveys, boys have a higher **prevalence** rate of **disability** than girls. Based on estimates from the SIPP, 8.5 million children and youth 21 years and younger have a disability. Boys and young men (12%) are more likely than girls and young women (8%) to have a disability (McNeil, 1997). These gender differences hold true across the different age groups of children and youth, as shown in the chart below.

A combination of physiological, maturational, behavioral and social differences between girls and boys may account for these differences in prevalence rates. Girls may be less prone to disability because they have two X chromosomes which protect against certain conditions. Girls tend to mature more rapidly, making them better able to handle early school environments where disabilities are often identified. Differences in behavior in school settings may also predispose boys to being identified as having a disability [U.S. Dept. of Education, Office of Special Education and Rehabilitation (OSERS), 1998, pp. II27-30].

Lower disability rates are reported for girls than for boys.

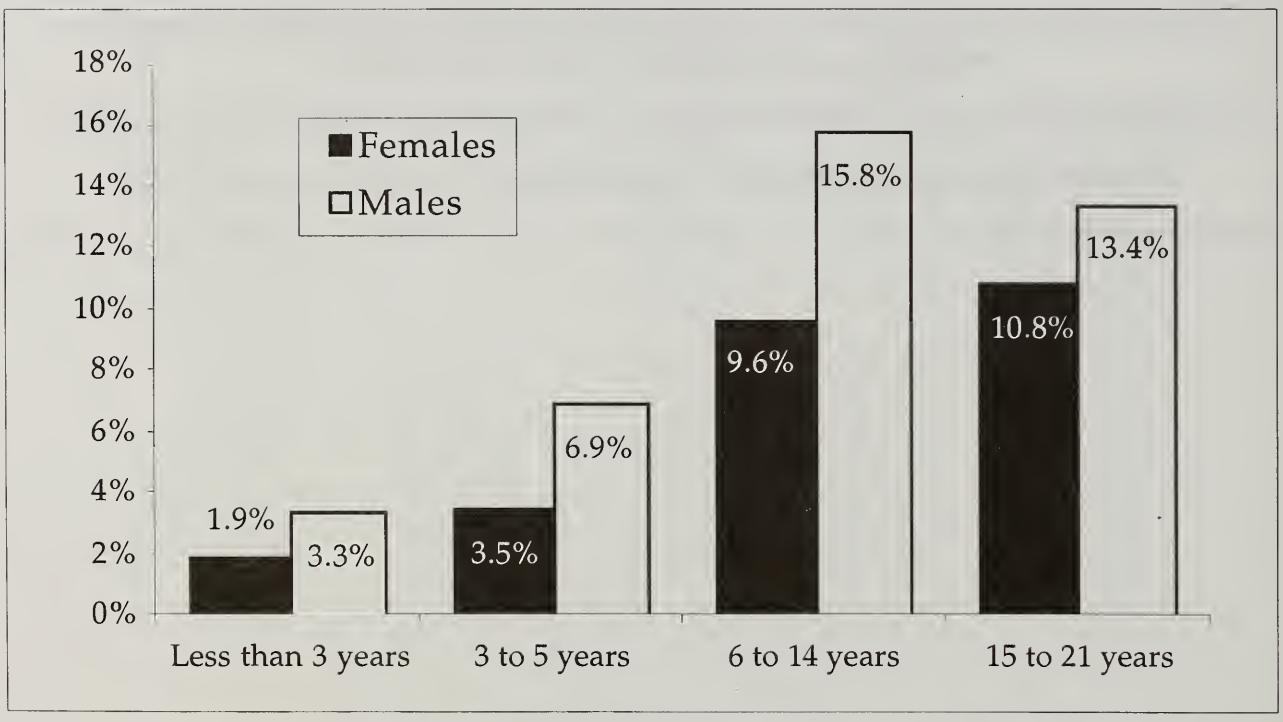


Figure 6: Disability rates for children and youth (0 to 21 years old) by age group and gender

Source: McNeil (1997). Website: http://www.census.gov/hhes/www/disable/sipp
Survey: SIPP, 1994-95

What are the conditions that cause activity limitations in girls and boys?

Together, seven conditions account for more than two-thirds (68.6%) of the main conditions that cause **activity limitations** among children under 18 years. These conditions, shown in the chart below, include respiratory diseases (mainly asthma), mental retardation, mental disorders, speech impairments, nervous system diseases, hearing impairments, and orthopedic impairments.

Boys have higher rates of mental disorders and speech impairments, and slightly higher rates of respiratory diseases and mental retardation. In contrast, girls show higher rates of nervous system diseases, hearing impairments, and orthopedic impairments.

Respiratory diseases (primarily asthma) account for one-quarter of the main conditions that cause activity limitations among children.

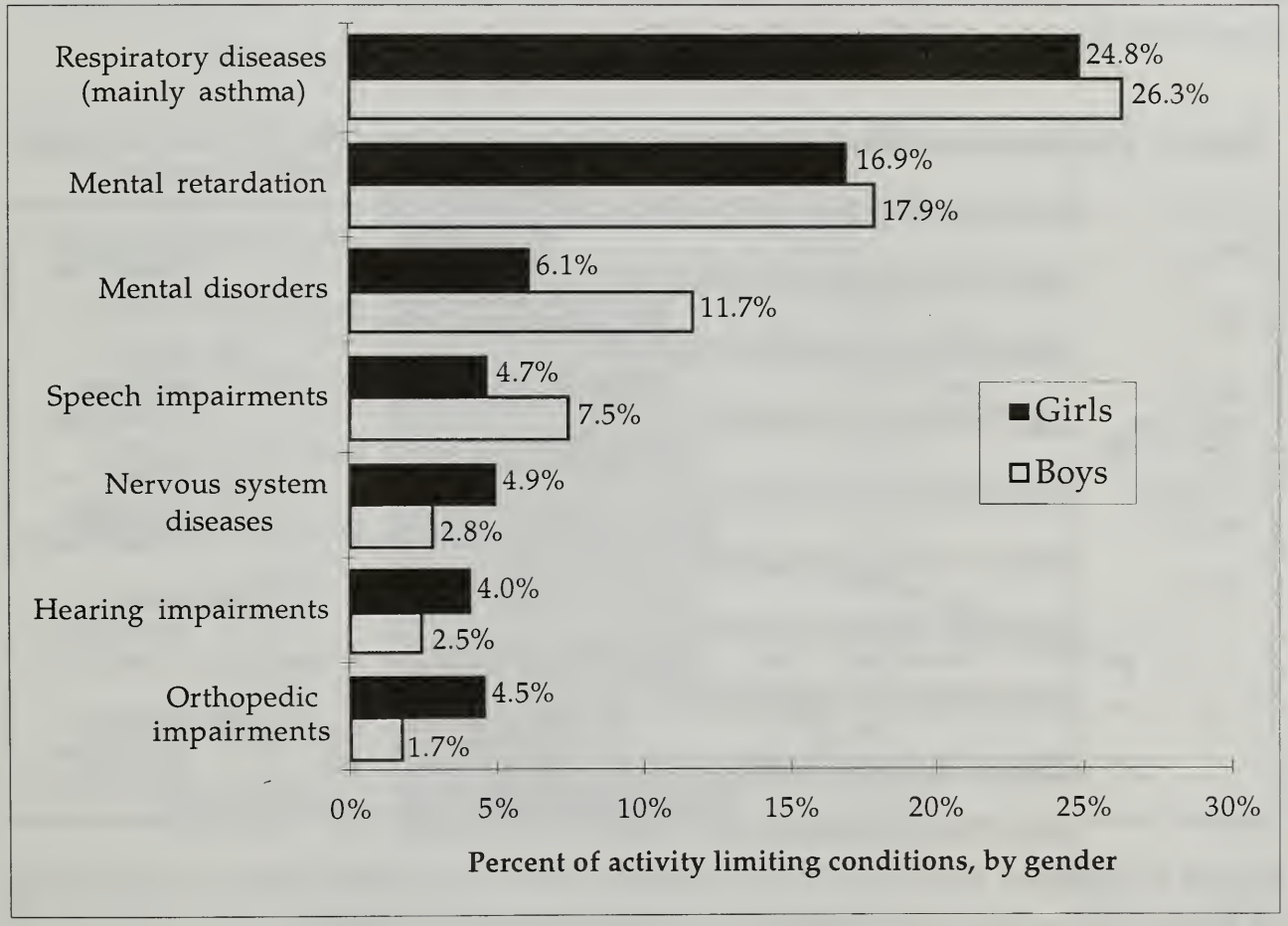


Figure 7: Activity-limiting main conditions with highest prevalence for children under 18, by gender

Source: LaPlante & Carlson (1996), Table 6a, pp. 95-104.
Survey: NHIS, 1992

Over the past two decades, has enrollment in federally funded special education changed in relation to total public school enrollment?

Under the Individuals with Disabilities Act (**IDEA**), all **children with disabilities** are entitled to a free and appropriate education designed to meet their unique needs. In the school year ending 1996, 5.6 million children and youth, 3-21 years, received **special education** services, funded by IDEA, Part B. Since 1977, enrollment in federally funded special education programs has increased at a greater rate than total public school enrollment. Between 1977 and 1996, the number of students in special education grew 52%, while total public school enrollment increased by 1%.

The chart below shows enrollment in special education as a percentage of total public school enrollment from 1977 to 1995, by type of disability. In 1995, children with disabilities in special education programs represented 12% of all students, up from 8% in 1977. Most of this increase was due to a dramatic rise in enrollment of students with specific learning disabilities, which rose from 1.8% of total public school enrollment in 1997 to 5.6% in 1995.

Special education enrollment increased substantially over the past two decades.

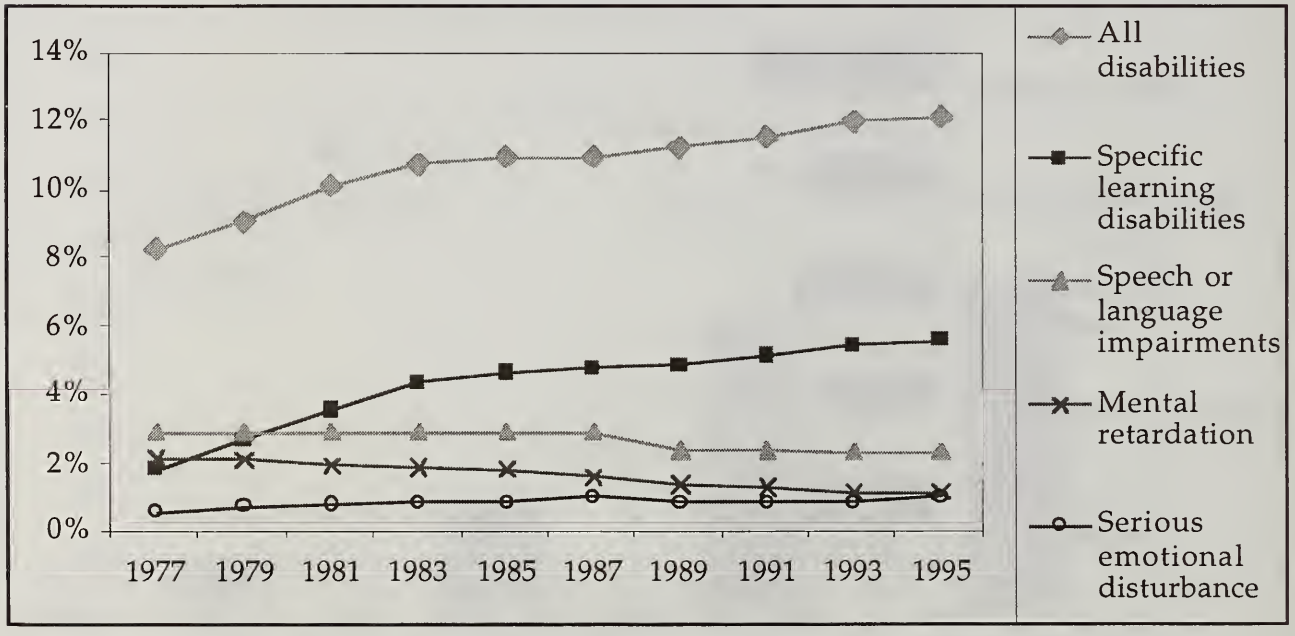


Figure 8: Children and youth (0 to 21 years old) in special education, as percentage of total public school enrollment, by disability type, 1977-1995

Sources: Website: http://www.nces.ed.gov/nces/pubs/ce/index.html; U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS: 1996, 1997); U.S. Department of Education, National Center for Education Statistics (1997, 1998).
Survey: U.S. Department of Education, Office of Special Education Programs, Data Analysis System

Do girls and boys have different rates of participation in special education?

Although girls and boys are equally represented in the school-age population, boys comprise about two-thirds of students in **special education**. The chart below shows that the greatest discrepancies exist in the categories of learning disability and emotional disturbance, which have the most broadly defined eligibility criteria. Girls in special education score lower on IQ tests, and were reported to have disabilities at earlier ages, both of which suggest more severe disabilities. In addition to possible physiological and maturational differences, school biases in identifying boys for special education may be a factor in these discrepancies. Once girls are in special education, they do as well or better academically as their male peers. Upon graduation from special education, however, girls are less likely to be employed, earn lower wages and are less likely to enroll in post secondary training or education (U.S. Department of Education, OSERS, 1998). These findings suggest a strong need for further research to investigate and find solutions to these problems.

About two-thirds of children in special education are boys.

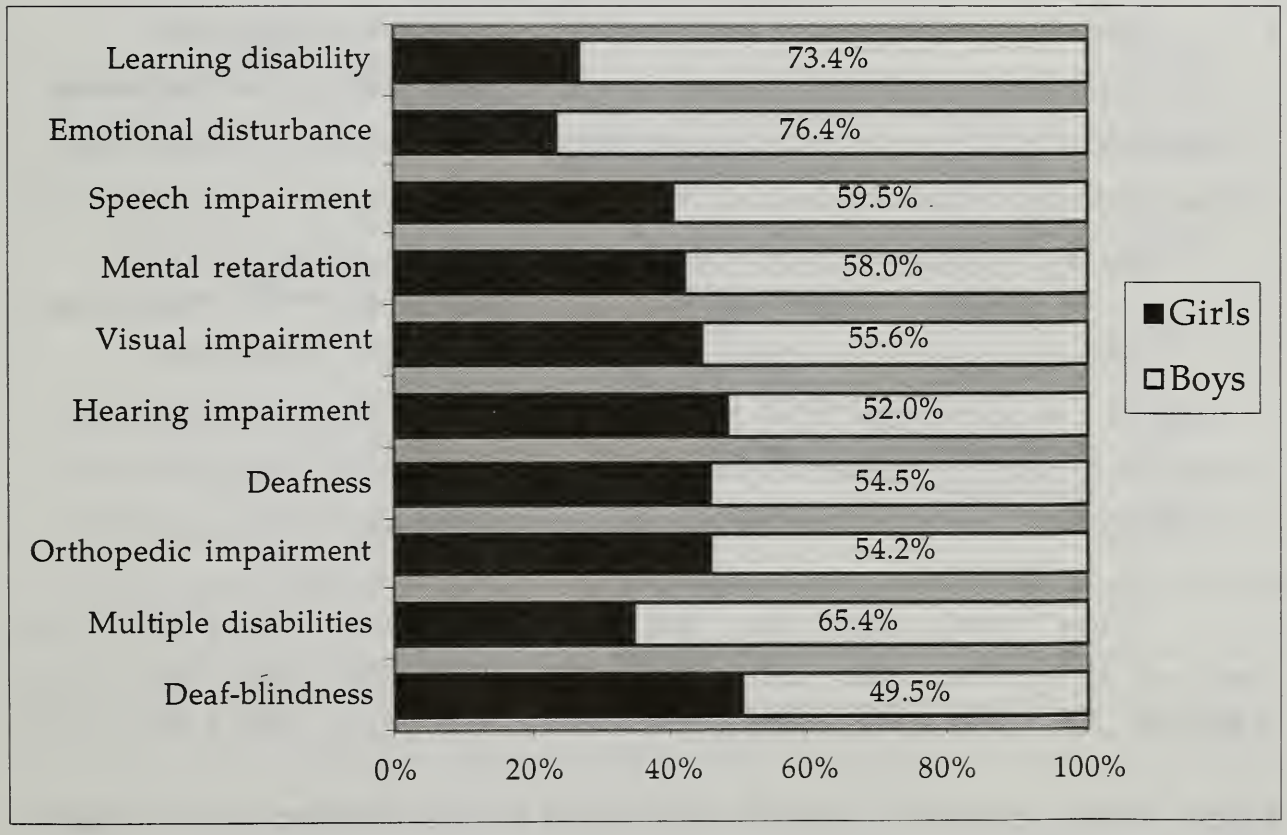


Figure 9: Percentage enrolled in special education, by gender and disability type

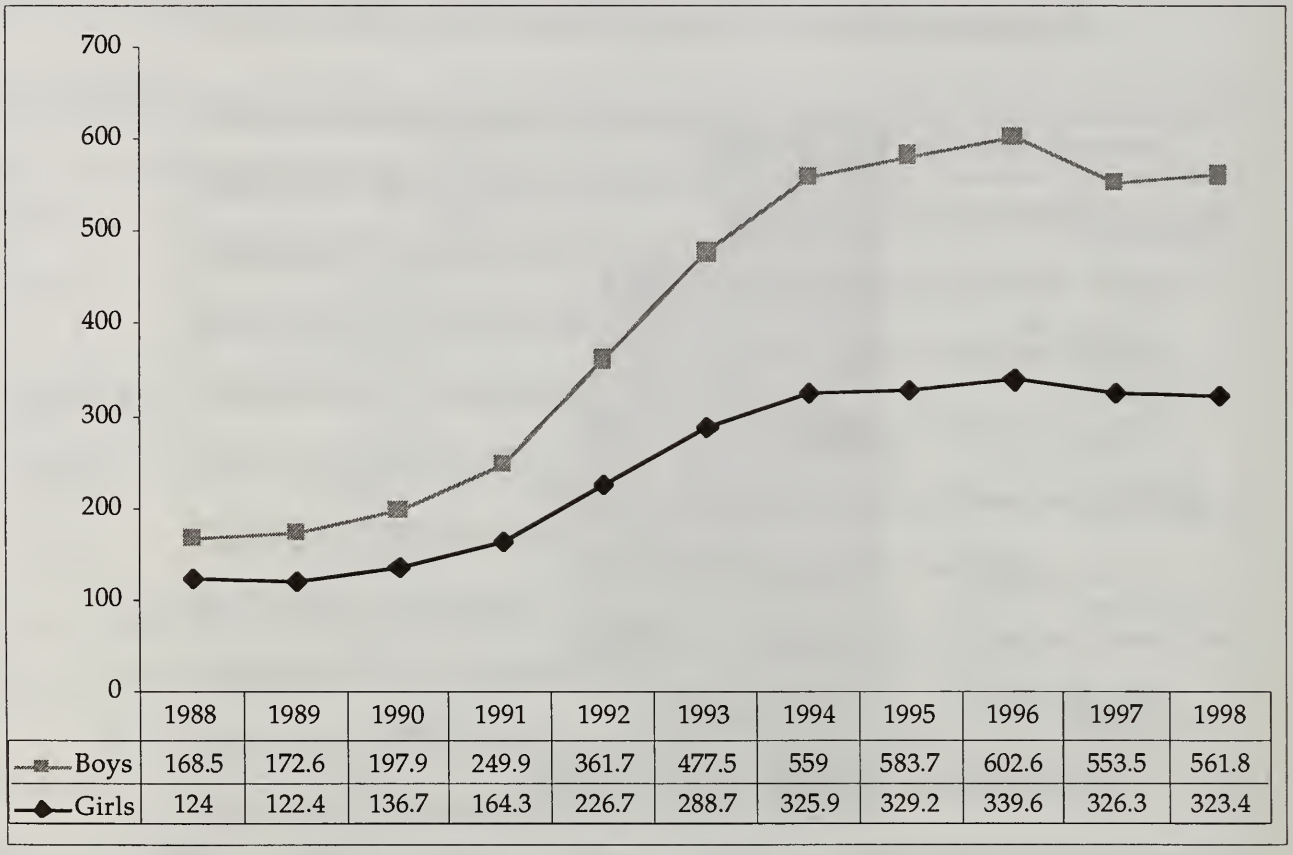
Source: U.S. Dept of Education, OSERS (1998); Valdes et al. (1990).
Survey: U.S. Department of Education, Office of Special Education Programs, Data Analysis System

Do more girls or boys receive Supplemental Security Income (SSI)?

Supplemental Security Income (SSI) is the primary program of federal benefits for children with disabilities and their families. In 1998, 885,250 blind and disabled children under 18 years old were receiving SSI nationwide. Of these, the large majority (63.5%) were boys; just over one-third (36.5%) were girls (Pickett, 1998, December).

Over the decade from 1988 to 1998, fewer girls than boys received SSI, as shown in the chart below. Although surveys such as the **Survey of Income and Program Participation (SIPP)** and the **National Health Interview Survey (NHIS)** indicate higher rates of disability for boys than girls, this alone does not account for the gap in SSI benefits between boys and girls that generally increased over the past decade. This is another area that bears further research.

More boys than girls receive SSI; and the gap has increased over the past decade.



	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
Boys	168.5	172.6	197.9	249.9	361.7	477.5	559	583.7	602.6	553.5	561.8
Girls	124	122.4	136.7	164.3	226.7	288.7	325.9	329.2	339.6	326.3	323.4

Figure 10: Number (in thousands) of blind and disabled children (0 to 17 years old) receiving SSI, by gender

Sources: Social Security Administration (1989-1998); Pickett (1998).
Website: http://www.ssa.gov/statistics/ores_home.html
Survey: Social Security Administration Program Data, 1988-1998

Section 3: Women: Disability, work, income and benefits

Women with disabilities confront many barriers to full participation in the work world. Information presented in Section 3 suggests that women with disabilities face "double jeopardy" in the workplace on the basis of both their gender and their disability status. As women, they are less likely to participate in the workforce, and they earn less than men. As people with disabilities, women face a lack of jobs, inaccessible work environments, and much lower wages than those with no disability.

Section 3 presents information about how many women with disabilities are working, their occupations, and their earnings relative to other groups. Women's experience with poverty, and differences in benefit levels and services, are also discussed.

Topic Questions

How often do women with disabilities have a job or business?

In which occupational categories are women with disabilities employed?

How often are women with disabilities employed in computer-related jobs?

Does labor force participation of people with a work disability differ by gender?

How do median earnings for women with and without disability compare to men's earnings?

How many women with a work disability are living in poverty?

Do women and men with a work disability differ in benefits they receive?

Are there gender differences in Social Security benefits for disabled workers?

Are there gender differences in people served by Vocational Rehabilitation?

How often do women with disabilities have a job or business?

Whether or not they have a **disability**, women are less likely than men to have a job or business, according to data from the **Survey of Income and Program Participation (SIPP**: 1994-95). When considering gender and severity of disability among people 21 to 64 years, severity of disability has the largest impact on employment: Only 24.7% of women with a **severe disability** and 27.8% of men with a severe disability had a job or business. **Non-severe disability** also adversely impacts the likelihood of working, particularly for women. Among those with a non-severe disability, 68.4% of women and 85.1% of men were working at a job or business. In comparison, 74.5% of women with no disability and 89.8% of men with no disability were working.

Less than one-quarter of women with severe disabilities have a job or business.

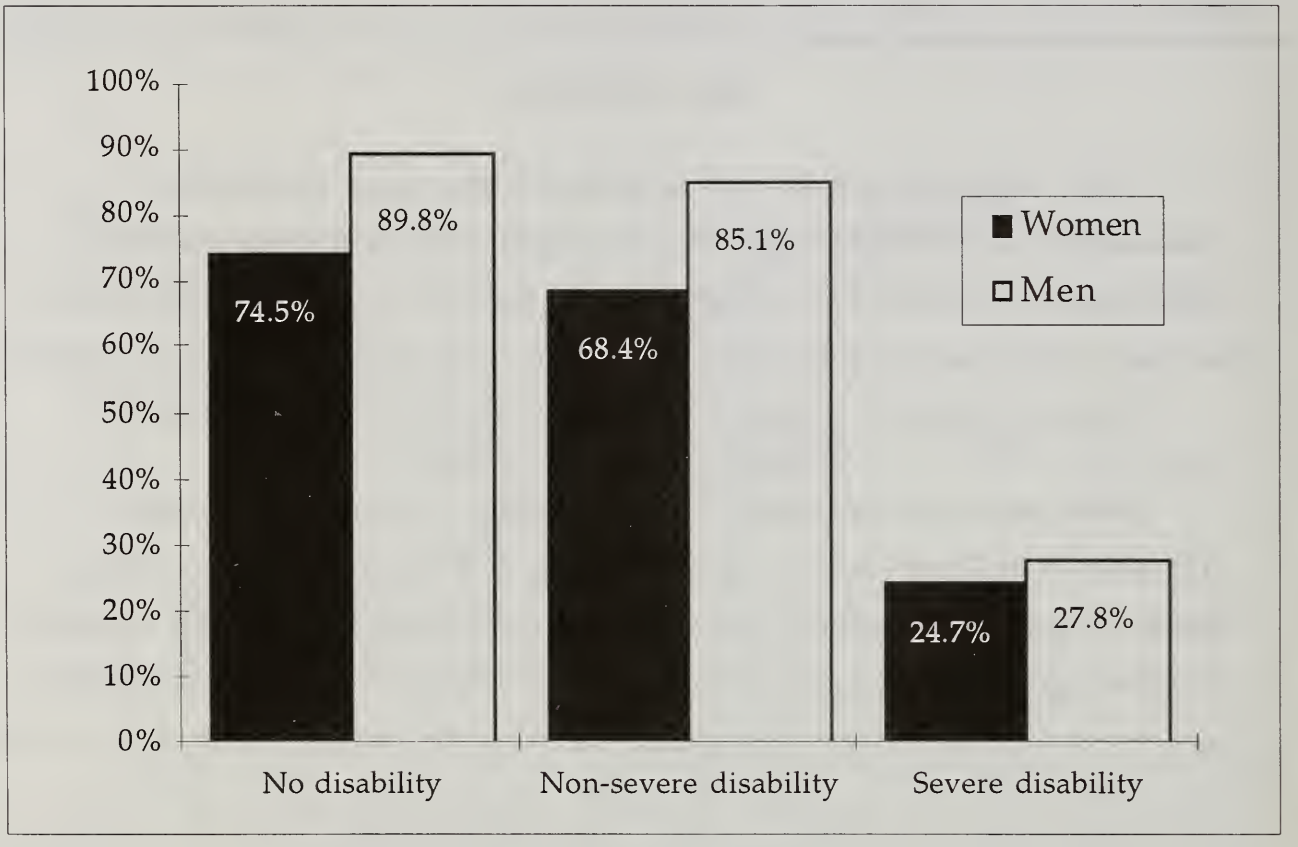


Figure 11: Percentage with job or business, by disability status and gender, 21 to 64 years old

Source: McNeil (1997). Website: http://www.census.gov/hhes/www/disable/sipp
Survey: SIPP, 1994-95

In which occupational categories are women with disabilities employed?

There are six major occupational categories used in **the Survey of Income and Program Participation (SIPP)**. Figures reported here are for people 16 to 64 years old, based on the 1994-95 SIPP. About 29.1 million Americans are employed in the managerial and professional specialty occupations, which include executives, managers, engineers, scientists, teachers, health and other professionals. The category of technical, sales and administrative support, with 37.4 million employed, represents the largest occupational category. The rapidly growing service sector employs about 17 million people. The category of farming, forestry and fishing is the smallest group, with 1.9 million employed. Nearly 12 million people work in the precision production, craft and repair occupations, and 19.3 million work in the factory-related category of operators, fabricators and laborers. People in the military are not included in this analysis.

Compared to men, more women with disabilities are employed in the service occupations. Approximately 1.8 million women with disabilities are employed in the service sector, representing 18.7% of women working in that category. By comparison, about 1.1 million men with disabilities work in the service occupations, and they represent only 15.3% of men employed in that sector. Based on analysis of data from the **Current Population Survey (CPS)**, researchers have found that employment of women with disabilities has increased over the past few decades, in tandem with the growth of the service sector (Yelin, 1992; Yelin & Katz, 1994; Yelin 1996).

In the category of managerial and professional occupations, women with disabilities are also employed at higher rates and in greater numbers than men with disabilities. About 1.6 million women with disabilities represent 10.7% of the women employed in this category, compared to 1.3 million men with disabilities who represent 9.2% of men in the managerial and professional category. However, women with disabilities are represented in higher numbers primarily in the traditionally female-dominated professions, including registered nurses and similar health professionals, elementary and secondary school teachers, and librarians. Women with disabilities also outnumber men with disabilities in middle management positions.

(Continues on following page.)

Compared to men, women with disabilities are employed at higher rates and in greater numbers in the services and the managerial and professional occupations.

(numbers in 1000's)		Women			Men		
Occupational category	Total	Total women	# with disability	% with disability	Total men	# with disability	% with disability
Managerial & professional	29,083	14,860	1,592	10.7%	14,223	1,315	9.2%
Technical, sales, administrative support	37,378	24,610	3,085	12.5%	12,769	1,767	13.8%
Service occupations	17,000	9,790	1,830	18.7%	7,209	1,105	15.3%
Farming, forestry & fishing	1,916	368	68	18.6%	1,548	306	19.8%
Precision production, craft & repair	11,978	1,104	166	15.1%	10,874	1,562	14.4%
Operators, fabricators & laborers	19,330	4,852	872	18.0%	14,477	2,309	15.9%
Totals	116,685	55,585	7,613	13.7%	61,100	8,362	13.7%

Table 2: Number and percentage of people with disabilities in major occupational categories, by gender, 16 to 64 years old

Source: J. McNeil (personal communication, January, 1999)
Survey: SIPP, 1994-95 (unpublished data)

How often are women with disabilities employed in computer-related jobs?

Women, with and without disabilities, have fewer jobs in the emerging computer industry. As shown in the chart below, women as a group also work more often in the lower-paying jobs as computer equipment operators than in the more lucrative jobs as computer programmers or scientists. Fewer women with disabilities work as computer operators (28,700, or 8.3% of women in the job category), compared to 40,000 men with disabilities (14.2% of men in the category). Computer programming employs only about 9,300 women with disabilities, or 5.6% of women in the category. Many more men with disabilities work as computer programmers (45,400 men or 10.3% of men in the category). Approximately 51,400 women with disabilities work as computer scientists, representing 16.8% of the women in the category. By comparison, about 58,000 men with disabilities work as computer scientists, but they represent only 7.5% of men working in this category.

Women with disabilities are underrepresented as computer programmers and computer equipment operators, compared to men with disabilities.

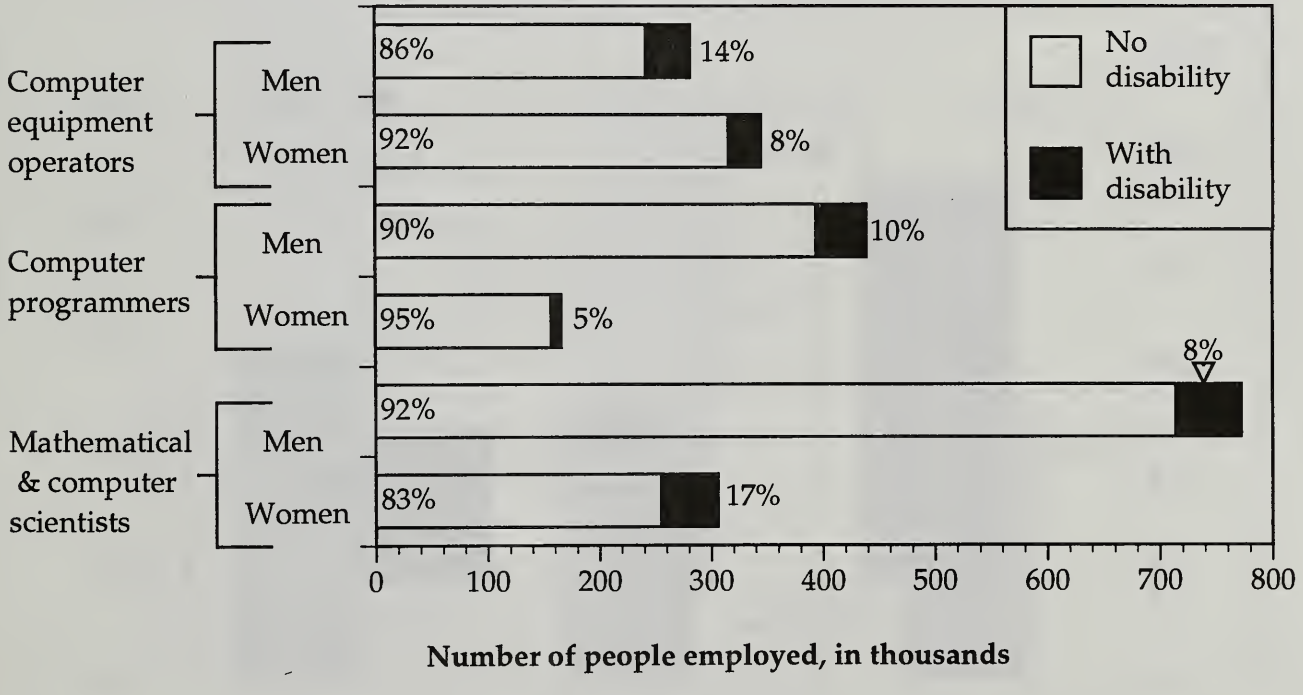


Figure 12: Number and percentage of people with and without disabilities in computer-related job categories, by gender, 16 to 64 years old

Source: J. McNeil (personal communication, January, 1999)
Survey: SIPP, 1994-95 (unpublished data)

Does labor force participation of people with a work disability differ by gender?

Work disability is another important disability measure that has not yet been described in this chartbook. The **Current Population Survey (CPS)** asks people whether they have a condition that limits the kind or amount of work they do. In 1998, 17.2 million people, or 9.9% of the working age U.S. population (16-64 years) had a work disability.

In general, more men than women participate in the **labor force**, and this is true for people with and without work disabilities. For both men and women, **labor force participation** is much lower among those with a work disability. In 1998, among working age people, only 2.5 million or 28.5% women with a work disability and only 2.7 million or 32.3% of men with a work disability participated in the labor force. In contrast, 59.7 million or 75.8% of women with no work disability and 68.2 million or 89.1% of men with no work disability participated in the labor force.

For both women and men, work disability dramatically lowers labor force participation rates.

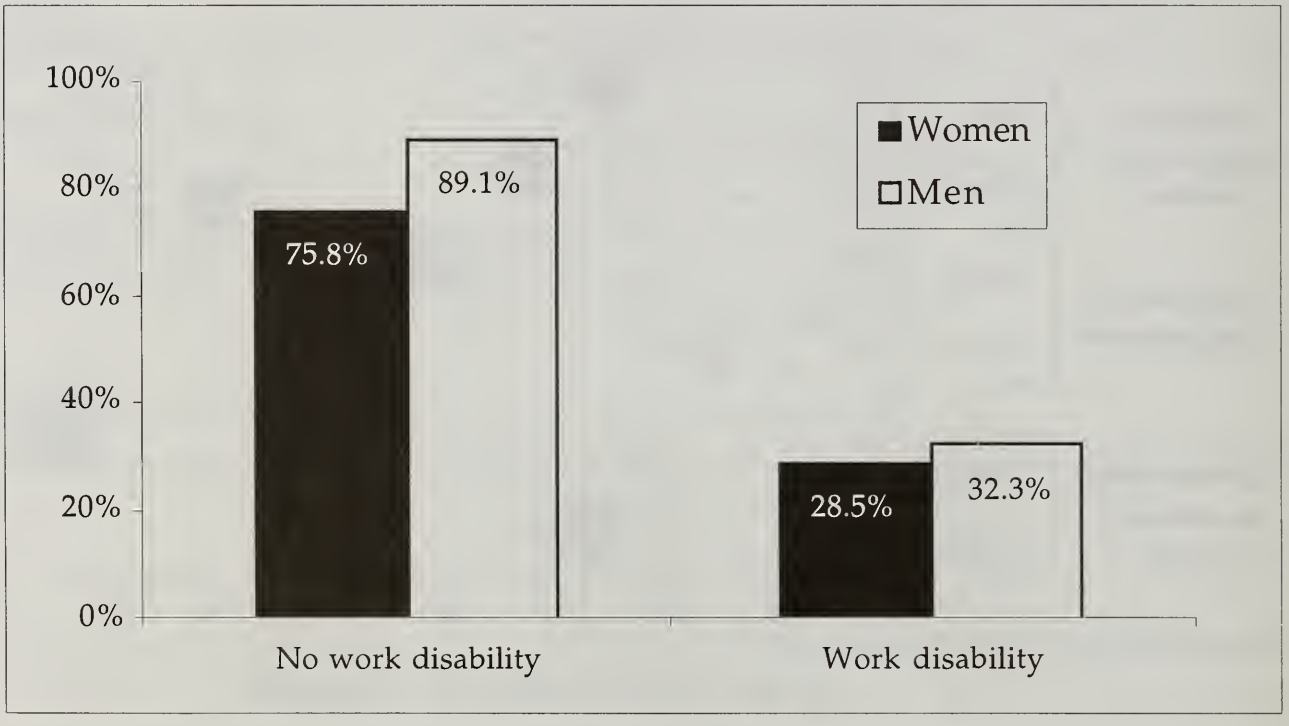


Figure 13: Percentage participating in labor force, by work disability status and gender, 16 to 64 years old

Source: U.S. Bureau of the Census Website, Table 298.
Website: http://www.census.gov/hhes/www/disable/cps/cps298
Survey: CPS, 1998

How do median earnings for women with and without disability compare to men's earnings?

Working women, ages 21 to 64, earn less than working men, regardless of disability category. Women with a **disability** (as defined by the **Survey of Income and Program Participation**) also earn less than women with no disability.

In 1994-95, men with no disability earned 49% more than women with no disability. (Median monthly earnings were $1,470 for women and $2,190 for men.) Among people with a **non-severe disability**, men earned 55% more than women ($1,200 for women; $1,857 for men). Women with a **severe disability** had the lowest earnings of any group. The median monthly earnings for women with severe disabilities amounted to $1,000, compared to $1,262 for men with severe disabilities. It is also interesting to note that median earnings of men with severe disabilities were slightly higher than earnings of women with non-severe disabilities.

Median monthly earnings for women are much lower than men's earnings; women with severe disabilities have the lowest median income.

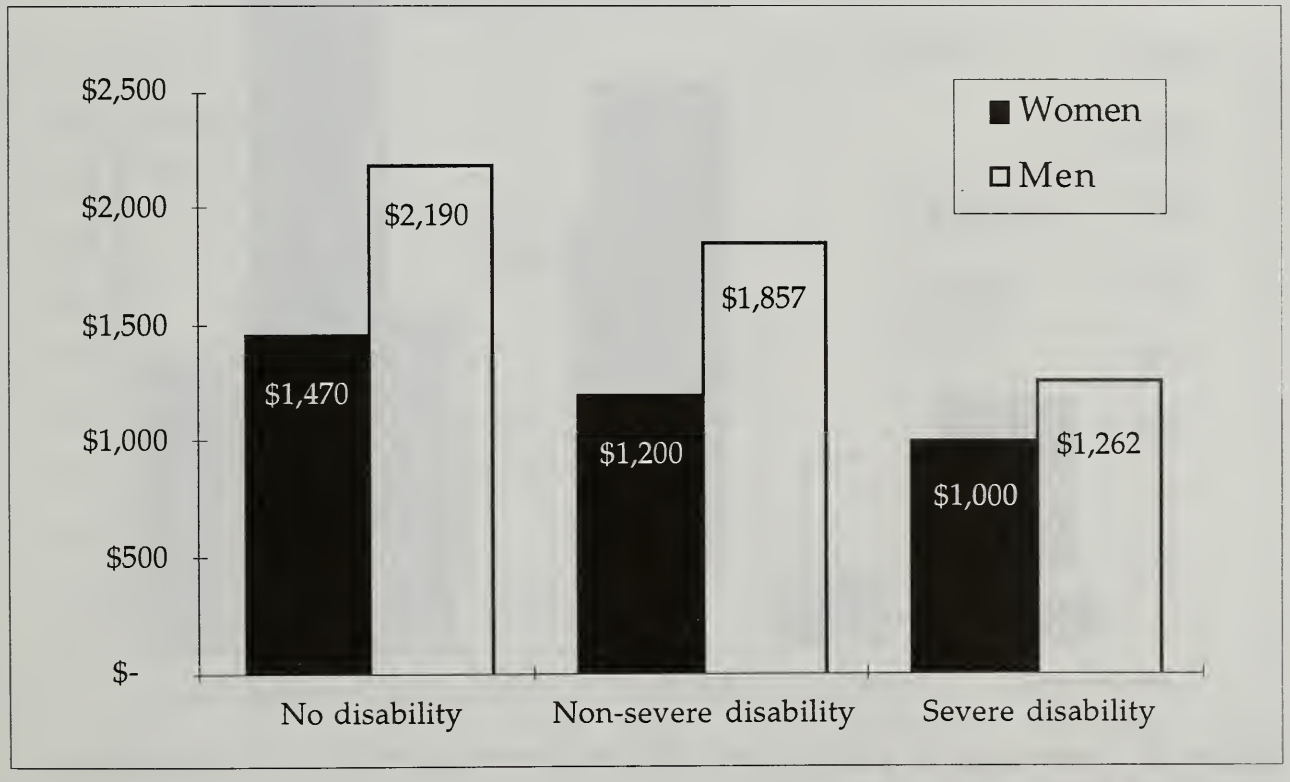


Figure 14: Median monthly earnings, by disability status and gender, 21 to 64 years old

Source: McNeil (1997). Website: http://www.census.gov/hhes/www/disable/sipp
Survey: SIPP, 1994-95

How many women with a work disability are living in poverty?

Women are more likely to be living in **poverty** than men, and people with a **work disability** are much more likely to be living below the poverty level than those with no work disability. Based on **CPS** estimates from 1992, women with a work disability, aged 16 to 64 years, have higher poverty rates (33.8%) than men with a work disability (24.2%). Women with **severe work disability** (a condition that prevents them from working) have the highest poverty rates of all. About forty percent (40.5%) of women with a severe work disability are living in poverty, compared to 31.2% of men with a severe work disability. Further research is needed to better understand and address these striking disparities.

One-third of women with a work disability live in poverty; rates are even higher for those with a severe work disability.

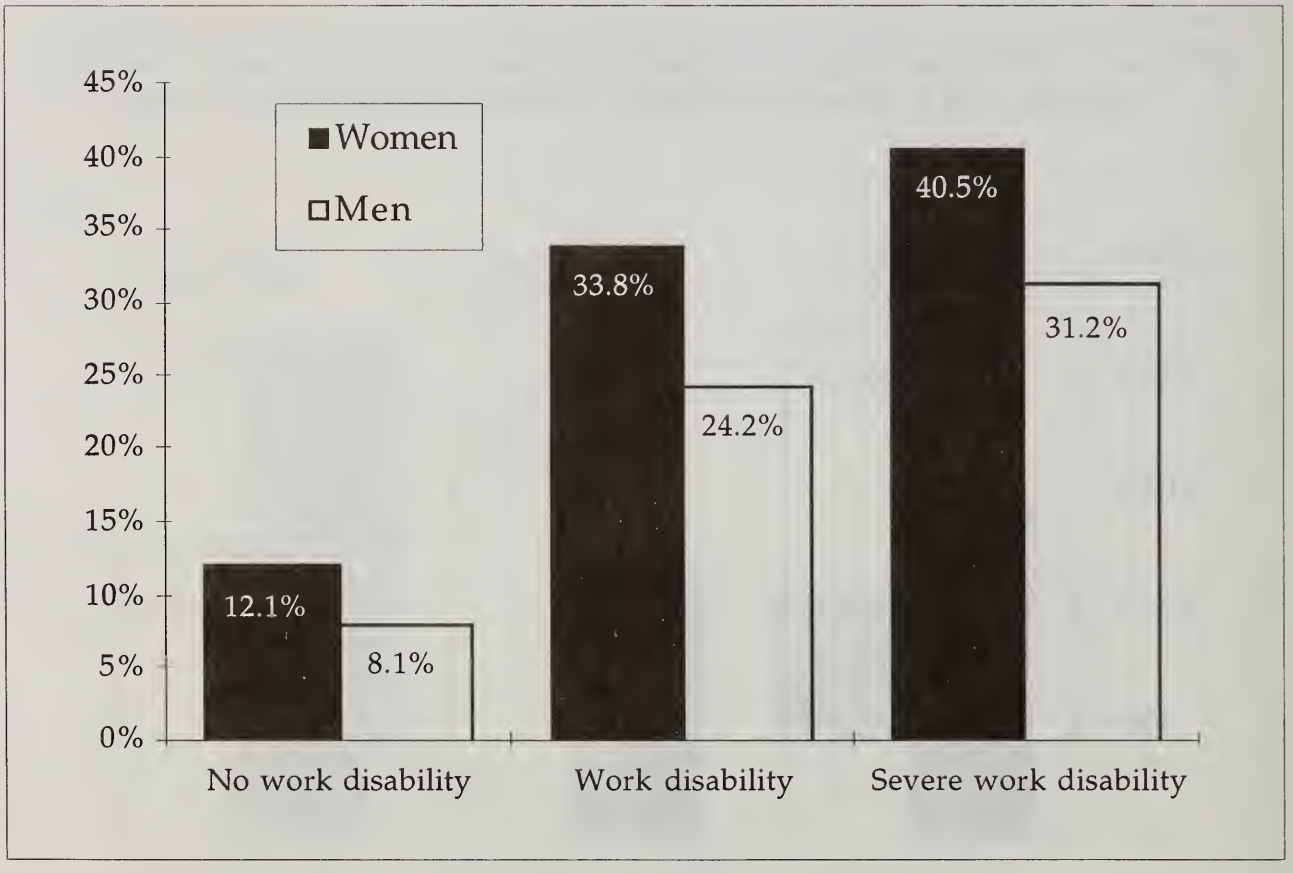


Figure 15: Percentage of people living below poverty level, by work disability status and gender, 16 to 64 years old

Source: U.S. Bureau of the Census (1993), Table 16, p. 91.
Survey: CPS, 1992

Do women and men with a work disability differ in benefits they receive?

Among people with a **work disability** in 1995, women received **Social Security benefits** at lower rates than men (25.6% of women, 30.6% of men). However, higher percentages of women receive need-based benefits, awarded only to people below a certain income level. More women than men receive food stamps (29.1% of women, 19.8% of men). More than one-third of women with a work disability receive Medicaid benefits, compared to about one-quarter of men with a work disability (36.2% of women, 27.2% of men). Higher percentages of work-disabled women live in public housing (6.8% of women; 4.4% of men) and subsidized housing (4.6% of women, 2.7% of men). These differences may be explained by a number of factors. Men may be more likely to have worked in jobs that make them eligible for Social Security benefits. Women's lower earnings are another factor. And, as described later in Section 4, women's higher rates of caring for children under 18 may make women eligible for more need-based benefits, compared to men.

Among people with a work disability, women have lower rates of Social Security income, but higher rates of other need-based benefits.

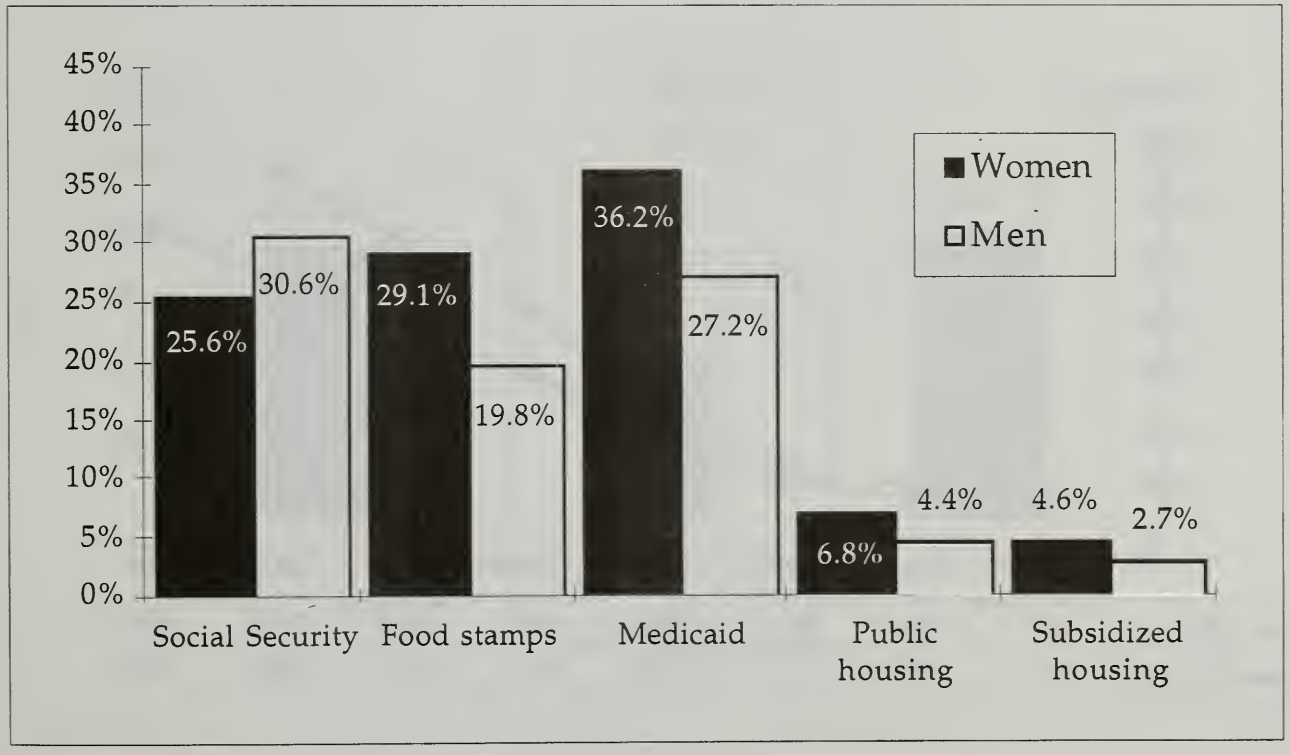


Figure 16: Percentage of people with work disability participating in assistance programs, by gender

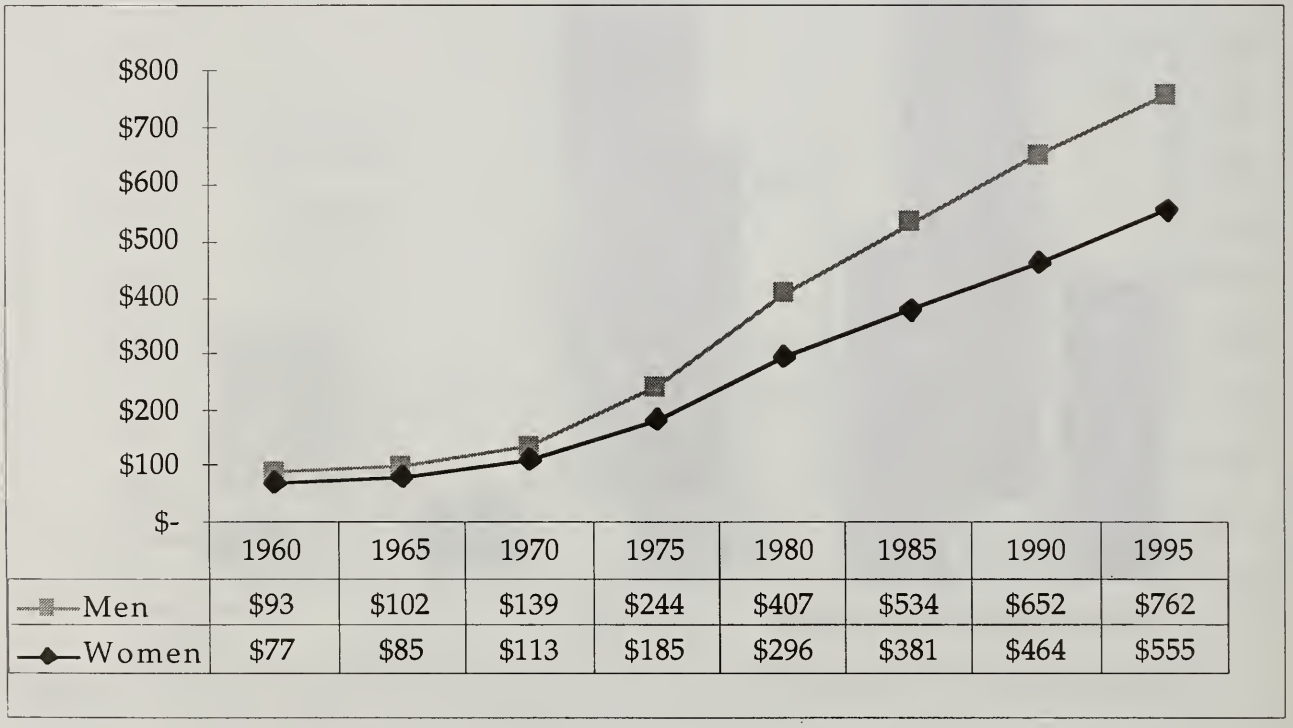
Source: U.S. Bureau of the Census (1997), Table 599, p. 384 .
Survey: CPS, 1995

Are there gender differences in Social Security benefits for disabled workers?

As of 1997, 4.5 million Americans received benefits as **disabled workers** under the Social Security **Old Age, Survivors and Disability Insurance (OASDI)** program. Disabled workers represented 10.0% of the total beneficiaries of OASDI and 15% of the people who were awarded OASDI benefits in 1997. Disabled workers are people under age 65 who have earned at least a certain minimum amount of wages in employment covered under Social Security and who qualify as disabled under Social Security criteria. They generally receive income from **Social Security Disability Insurance (SSDI).**

Many more men than women receive OASDI disabled worker benefits. In 1997, 59% of those receiving benefits were men (2.7 million men, compared to 1.8 million women). For men, the average monthly benefit in 1997 was $810, while for women it was only $595. Benefits have been consistently higher for men over four decades. The gap between the average monthly awards of men and women has also grown since 1970, as shown in five-year increments in the chart, below.

On average, men receive higher disabled worker benefits, and the gap between men and women has increased over the past 25 years.



	1960	1965	1970	1975	1980	1985	1990	1995
Men	$93	$102	$139	$244	$407	$534	$652	$762
Women	$77	$85	$113	$185	$296	$381	$464	$555

Figure 17: Average monthly Social Security benefit for disabled workers, by gender, in five-year increments, 1960-95

Source: Social Security Administration (1997), Table 5.E2.
Survey: Social Security Administration Program Data, 1960-1995

Are there gender differences in people served by Vocational Rehabilitation?

The federal-state **Vocational Rehabilitation (VR)** program provides services for people with disabilities to assist in obtaining employment. The program served more than 1.2 million people in 1996. People with severe disabilities represented more than three-quarters of this group, 950,097 people or 77.5% of the total number of people served.

Women represented only 43.9% of the 589,472 cases closed in 1996. In that year, 213,790 people successfully competed their VR services **with employment outcome**, finding work in a variety of jobs. Of those whose cases were closed with employment outcome, 96,319 (45.1%) were women and 117,471 (54.9%) were men. Women also were less frequently represented among the cases that were closed because they were found to be not eligible after application to VR, as well as cases that were closed with the status of "no employment outcome." Further research is needed to better understand these gender differences.

Among Vocational Rehabilitation cases closed in 1996, fewer women had received services.

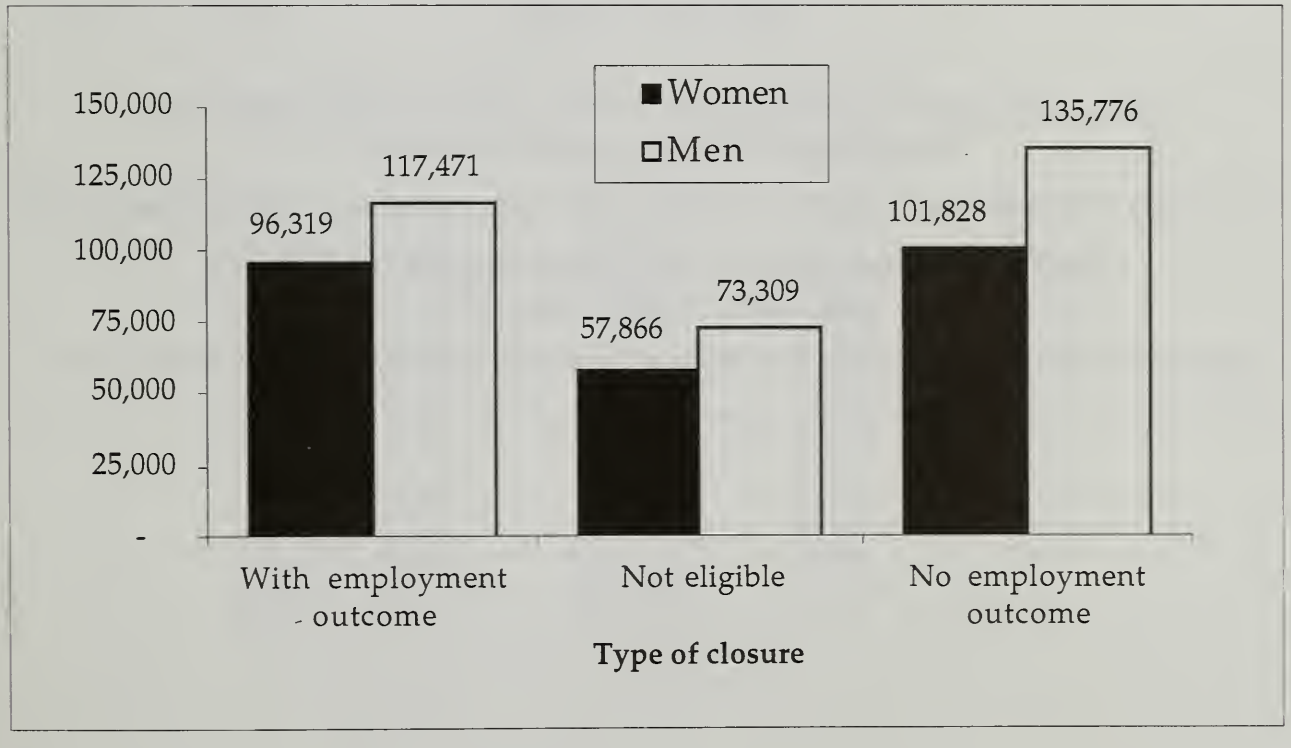


Figure 18: Number of Vocational Rehabilitation cases closed, by type of closure and gender

Survey: Rehabilitation Services Administration Program Data, FY1996.

Section 4: Living arrangements, family life, and medical experiences

The previous section presented data on the topics of gender, disability and work. Much less information, however, is regularly collected on a national level about other important issues that affect the lives of adult women with disabilities. Section 4 examines a number of topics related to women's participation in families, including marital status and parenting. Experiences related to the medical system are also included. The information included in this section is based on large, national surveys. For many related topics, no large federal-level survey data are available and data from smaller surveys cannot be generalized to the population as a whole. Therefore, many gaps exist in research on adult women with disabilities, and some of these research gaps are described in Section 7 of this chartbook. More research is needed on these and other barriers to the full participation of women with disabilities in society, community and family life.

Topic Questions

Are there differences in marital status among women and men with and without activity limitations?

What percentage of women and men with and without disabilities are parents?

Do medical expenditures differ among women and men with and without disabilities?

Do women with functional limitations receive appropriate cancer screening?

Are there differences in marital status among women and men with and without activity limitations?

Based on estimates from the 1992 **National Health Interview Survey (NHIS)**, married people constitute 65% of people in the civilian, **non-institutionalized** population of the United States, 18 years and older. However, analysis of the NHIS reveals that women with **activity limitations** have lower rates of being married, compared to other women and men with or without activity limitations. Only 50% or 9.1 million of the 18.2 million women with activity limitations are currently married. In contrast, 64% of women with no activity limitation, 68% of men with activity limitation, and 69% of men with no activity limitation are married. These differences are probably due to women's greater longevity, especially since the women with activity limitations have higher rates of being widowed. Only 44% of women with **severe activity limitations** (unable to carry on major activity) are married and these women have higher rates of being divorced than women with less severe limitations.

Women with activity limitations are less often currently married and more often widowed, compared to the other groups.

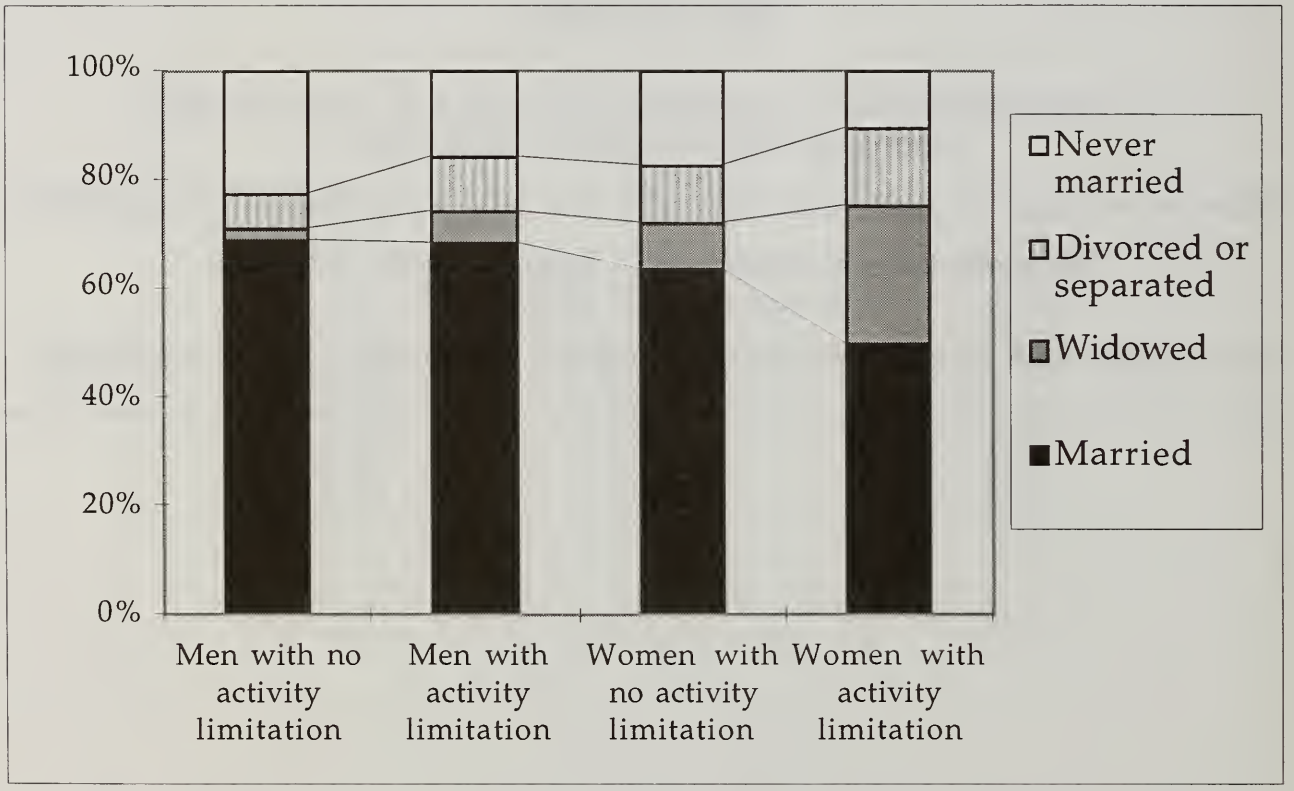


Figure 19: Marital status, by activity limitation status and gender, 18 and older

Source: LaPlante & Carlson (1996), Table 1.
Survey: NHIS, 1992

What percentage of women and men with and without disability are parents?

Based on estimates from the 1993 **SIPP**, about 6.9 million adults with a **disability** are parents. (For these estimates, a parent is defined as a adult between 18 and 64 years who reports having at least one child under 18 years in the home. Parents with stepchildren or adopted children under 18 are included but parents with grown children are not included.) These 6.9 million disabled parents represent about 11% of the total estimated population of 57.9 million parents. They represent about 30% of the approximately 23 million disabled adults between the ages of 18 and 64 years (Toms-Barker & Maralani, 1997).

The National Resource Center on Parents with Disabilities at Through the Looking Glass (TLG) analyzed the SIPP data on parenting. Women, regardless of their disability status, are more likely than men to have children at home. [LaPlante, Carlson, Kaye, and Bradsher (1996) also found that women were more often single parents.] One-third of women with disabilities (33%) have children at home, compared to about one-quarter (26%) of men with disabilities. Gender differences are even greater for the subset of people with **severe disabilities**, with nearly one third of women (31%) but only 18% of men parenting minor children.

Regardless of their disability status, higher percentages of women are parenting children under the age of 18, compared to men.

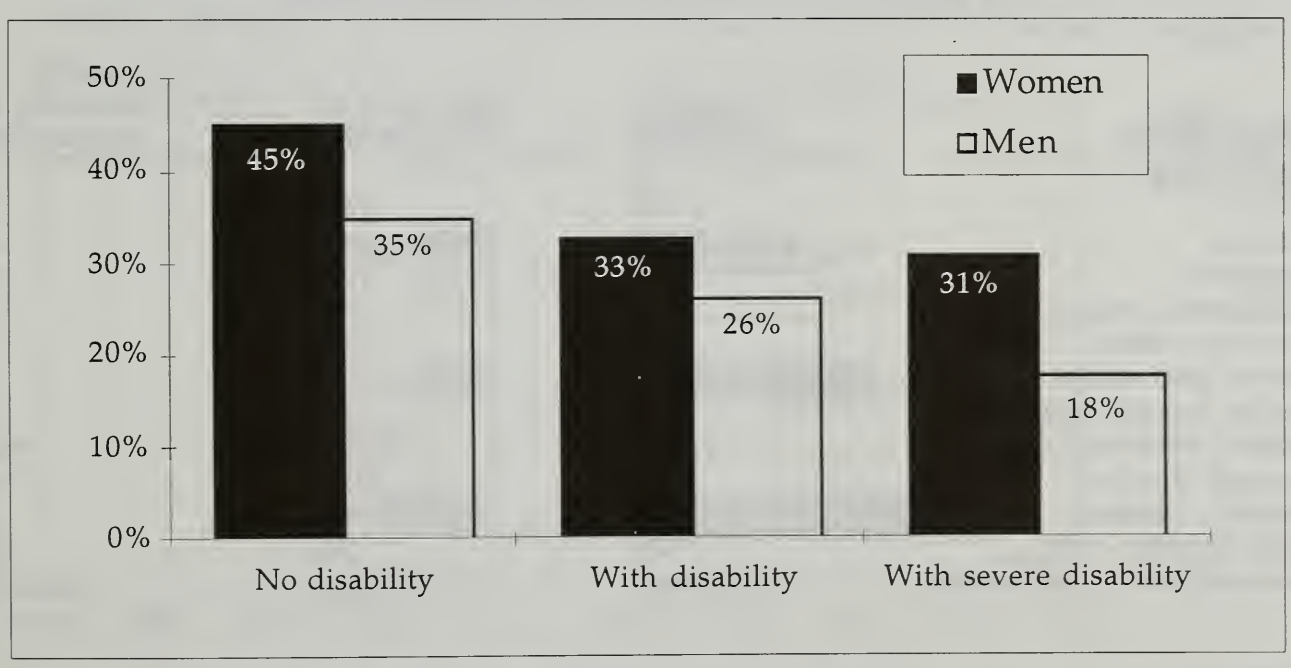


Figure 20: Percentage of adults with children under 18 years old in home, by disability status and gender

Source: Toms-Barker & Maralani (1997). (See TLG Website: http://www.lookingglass.org)
Survey: SIPP, 1993

The National Resource Center on Parents with Disabilities compared parents with a **disability** with two other groups: parents with no disability and adults with a disability who are not parents. The data are summarized in the table below. Compared to parents with no disability, parents with a disability were found to be economically and educationally disadvantaged, reporting lower incomes, higher rates of public assistance, higher high school drop-out rates and lower college attendance. Interestingly, more than one-quarter (26%) of parents with a disability report that their spouse has a disability, compared to only 8% of non-disabled parents. In addition, 14% of parents with disabilities had a child with a disability, compared to only 3% of non-disabled parents. This may be due in part to parents with a disability adopting or providing foster care to children with a disability.

Among people with a disability, parents were younger and more likely to be married than non-parents, differences that are due primarily to the age of childbearing. Compared to adults with a disability who were not parents, a higher percentage of parents with a disability had attended college and were employed. Although average monthly income was slightly higher for parents than non-parents, the parents also had children to support. Larger family size may also explain the fact that parents had higher rates of receiving food stamps and housing assistance, compared to non-parents.

Parents with a disability differ demographically from parents with no disability and adults with a disability who are not parents

Characteristic	Parents with disability	Parents with no disability	Adults with disability who are not parents
Age (average)	39	36	48
White	70%	74%	77%
Married	73%	84%	47%
Employed	52%	78%	43%
High school dropout	29%	13%	33%
Attended college	37%	52%	31%
Receive food stamps	28%	10%	12%
Receive housing assistance	9%	4%	7%
Monthly household income	$2,892	$3,823	$2,728
Severely disabled	49%	N/A	61%
Spouse is disabled	27%	8%	39%
Have disabled child	14%	3%	N/A
Estimated total in population	6.9 million	51 million	16 million

Table 3: Characteristics of parents with disability, parents with no disability and adults with disability who are not parents

Source: Toms-Barker & Maralani (1997). (See TLG Website: http:/www.lookingglass.org)
Survey: SIPP, 1993

Do medical expenditures differ among women and men with and without activity limitations?

Medical expenditures of people with disabilities are four times greater than expenditures of people with no disabilities. Data collected in the 1987 **National Medical Expenditures Survey** was updated to 1993. In this survey, a person is considered to have a disability if she or he has an **activity limitation** in a major life area such as work, school or housework, due to a **chronic health condition** or impairment. Although people with disabilities constituted only 17% of the civilian, **non-institutionalized** population, they accounted for nearly half (47%) of medical spending. In 1993, this was estimated at $282.8 billion, spent on medical expenditures for people with disabilities (Trupin, Max & Rice, 1995).

As shown below, medical expenditures differ by age and gender. Not surprisingly, older people spend more on medical care than younger people. Males with disabilities have higher per capita expenditures than females with disabilities in all age groups except children. The difference is particularly striking in the 45 to 64 year old group, where per capita expenditures of men with disabilities ($6,100) are 40% higher than women's expenditures ($4,365). Nevertheless, gender differences are smaller than the differences between people with and without disabilities in all age and gender categories.

People with activity limitations spend dramatically more on medical care than those with no activity limitations, dwarfing the gender differences at all ages.

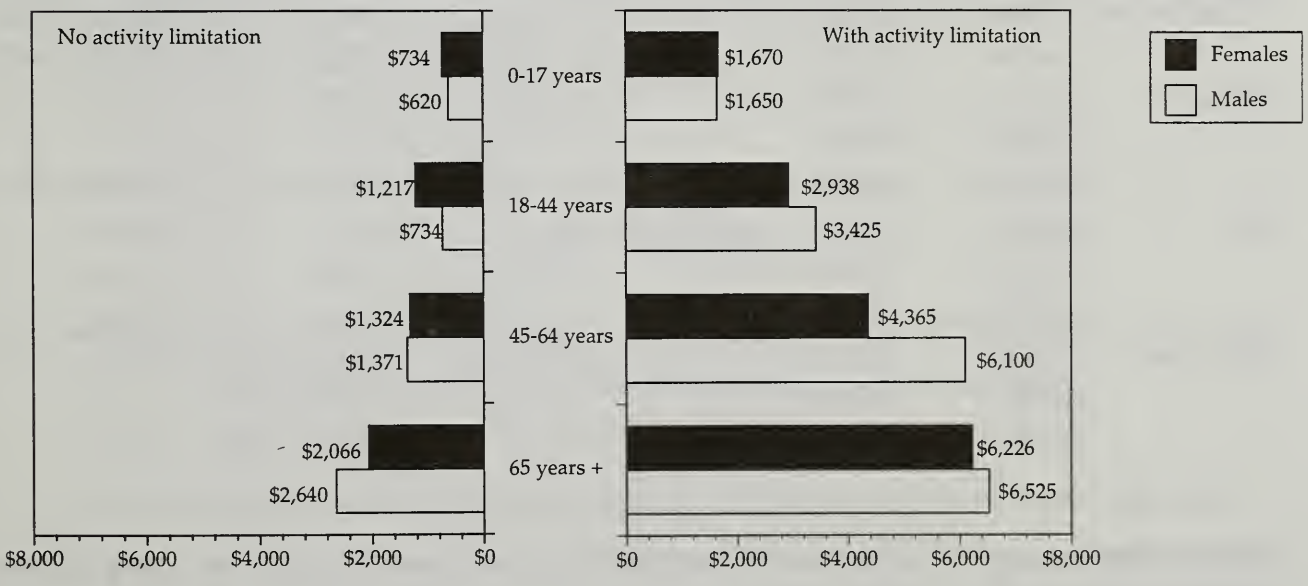


Figure 21: Per capita medical expenditures, by age group, activity limitation status, and gender

Source: Trupin, Rice, & Max (1995); Max, Rice, & Trupin (1995).
Survey: National Medical Expenditures Survey, 1987 (with data updated to 1993)

Do women with functional limitations receive appropriate cancer screening?

Women with disabilities share with other women the same basic health care needs, yet they often face barriers to obtaining preventative and other standard medical care. The United States has set Year 2000 national health objectives to promote preventative screening for reproductive system cancers, estimated to affect more than a quarter of a million women nationally (Wellner, 1998). The objectives are to ensure that (1) at least 85% of women 18 years and over will have received a Pap test for cervical cancer within the past 3 years, and (2) at least 80% of women 40 and over will have received a mammogram in their lifetime. Using the **National Health Interview Survey on Disability (NHIS-D)**, and the Health Promotion/Disease Prevention Supplement, researchers found that women with **functional limitations** were less likely than women with no functional limitations to have had a Pap test in the past 3 years. Women 65 years and over with functional limitations were less likely to have had a mammogram than those in the same age group with no functional limitations.

Women with functional limitations (particularly older women) are less likely to receive preventative screening for cervical and breast cancer.

Table 4: Pap test (Cervical cancer screening)

Age group	Functional limitation status	Percent had Pap test (past 3 years)
18 to 44	No FLs	80.2%
	1-2 FLs	77.8%
	3+ FLs	79.4%
44 to 64	No FLs	75.7%
	1-2 FLs	70.2%
	3+ FLs	74.4%
65+	No FLs	58.1%
	1-2 FLs	51.8%
	3+ FLs	46.0%
18+ (total)	No FLs	76.1%
	1-2 FLs	64.8%
	3+ FLs	60.6%

Table 5: Mammogram (Breast cancer screening)

Age group	Functional limitation status	Percent had mammogram (ever)
40 to 49	No FLs	77.6%
	1-2 FLs	75.7%
	3+ FLs	77.2%
50 to 64	No FLs	80.6%
	1-2 FLs	79.7%
	3+ FLs	80.9%
65+	No FLs	73.3%
	1-2 FLs	70.1%
	3+ FLs	64.7%
40+ (total)	No FLs	77.8%
	1-2 FLs	73.9%
	3+ FLs	70.9%

Table 4: Percentage of women who received Pap test (past 3 years), by age group & functional limitation status (FLs)

Table 5: Percentage of women who received mammogram, by age & FLs

Source: Nosek, Gill, & National Center for Health Statistics, CDC (1998).
Survey: NHIS-D, 1994

Section 5: Mental disorders and disability: Gender differences

Major national surveys are better at measuring disabilities due to physical conditions than disabilities due to mental disorders. People with mental disorders are a highly stigmatized group, and under-reporting almost certainly "conceals the true prevalence of mental disorders, the extent of disability and their combined impact on family and friends" (Kennedy, Carlson, Üstün, Regier, Norquist, Sirovatka, 1997, p. 133). In addition, some areas of daily living in which people with mental disorders typically experience limitation (notably, social relationships) are less clearly defined or measured as domains of disability. There is a corresponding lack of national-level information on the relationship between mental disorder and disability. However, a recent international study predicts that, within the next two decades, mental disorders will become the second leading worldwide cause of premature death and years lived with a disability (Murray and Lopez, 1996). For women, one mental condition, unipolar major depression, will become the single leading worldwide cause of premature death and years lived with disability, the same study predicts. These staggering figures point to the need for improved, nationally representative studies to better understand the disability impact of mental disorders.

In this section, nationally representative as well as smaller surveys are used to estimate the prevalence of mental disorders and ensuing disabilities among women and men. Limitations of the surveys are noted in the text and described in more detail in the Appendix. Clearly, more exploration is needed to understand gender differences in mental disorders as well as to evaluate existing services and develop new programs that meet the unique needs of women and men with disabilities due to mental disorders.

Topic Questions

Are women more likely than men to experience a mental or psychiatric disorder?

Do women use more mental health services than men?

What is the extent of disability due to mental disorders?

Are there gender differences in limitations due to serious mental illness?

Are women more likely than men to experience a mental or psychiatric disorder?

The **National Comorbidity Survey**, conducted in 1990-92, estimated that nearly half (47.3%) of all women between the ages of 15 and 54 have experienced a **psychiatric disorder** at some point in their lives. Lifetime prevalence rates for any psychiatric disorder were similar for men (48.7%). However, women more often suffered a depressive disorder (23.9% of women; 14.7% of men) or anxiety disorder (30.5% of women; 19.2% of men). In contrast, substance abuse disorders affect more men (17.9% of women; 35.4% of men). Women were more likely to have experienced three or more psychiatric disorders in a lifetime (16% of women; 13% of men: National Center for Health Statistics, 1996). National and international studies found that women experience more years of disability due to depression, while men experience more alcohol-related disability (Murray & Lopez, 1997; Rhodes & Goering, 1997).

Estimating prevalence rates for **mental disorders** during a one-year period, the **Epidemiological Catchment Area Survey** found that 51.3 million people or 28.1% of adults had a mental disorder in 1990 (Bourdon, Rae, Narrow, Mandersheid, & Regier, 1994). About 5 million people, (2.8% of adults) experienced **severe mental disorders** (National Advisory Mental Health Council, 1993).

Rates of depressive and anxiety disorders are higher for women, while men experience more substance abuse disorders.

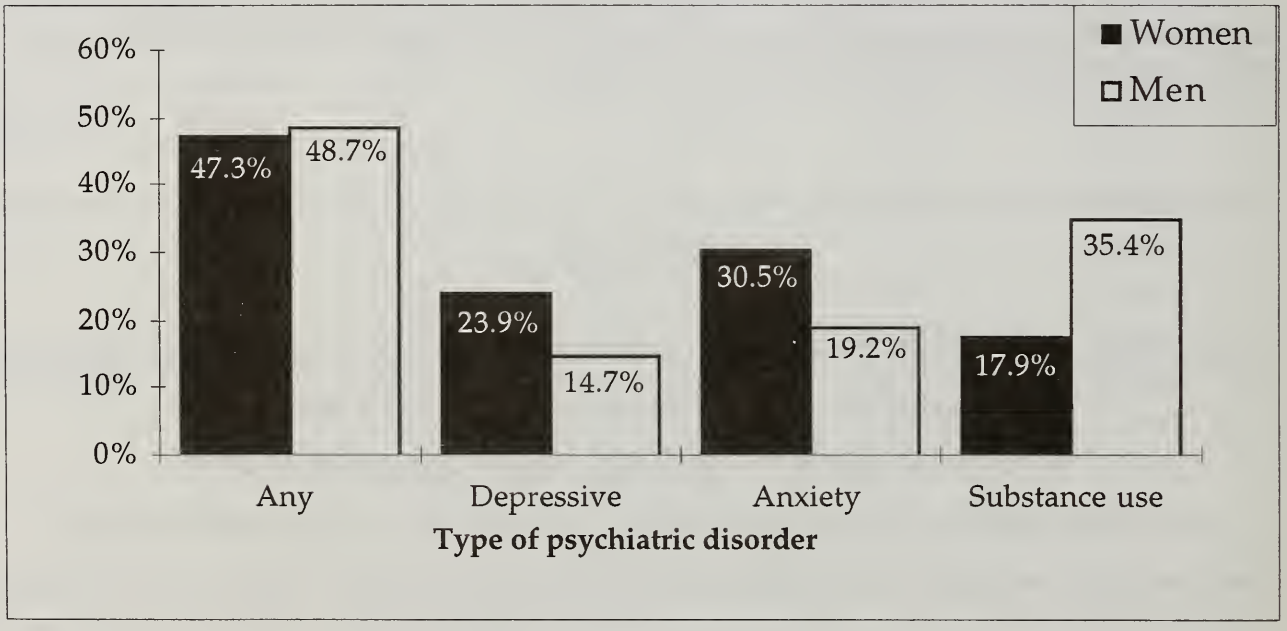


Figure 22: Lifetime prevalence of certain types of psychiatric disorders, by gender

Sources: National Center for Health Statistics (1996); Kessler, McGonagle, Zhao, et al. (1994)
Survey: National Comorbidity Survey, 1990-92

Do women use more mental health services than men?

Using the **National Comorbidity Survey (NCS)** to measure lifetime prevalence and service use, researchers have found women more likely to seek treatment for mental disorders. Of women, 15 to 54 years, who reported an episode of psychiatric disorder in their lifetime, more than half (55.1%) had received mental health services. In contrast, 42.3% of men with an episode of mental disorder had received treatment. Of course, not all mental disorders are serious and some improve without treatment. In this survey, mental health services were defined broadly to include self-help groups, clergy, social workers, hotlines, spiritualists and herbalists as well as health providers such as physicians and psychologists. Nearly half of the women (46.6%) had sought help from a health service professional, compared to less than one-third of the men (31.5%). Women were also more likely to utilize human services providers, including social service agencies, religious counselors, hotlines and school counselors (24.2% versus 16.6%). Men were slightly more likely than women to use self-help groups (16% of men versus 14%). This may be related to men's higher substance abuse prevalence rates, as there are many self-help groups for substance abuse.

Women are more likely than men to receive treatment for mental disorders.

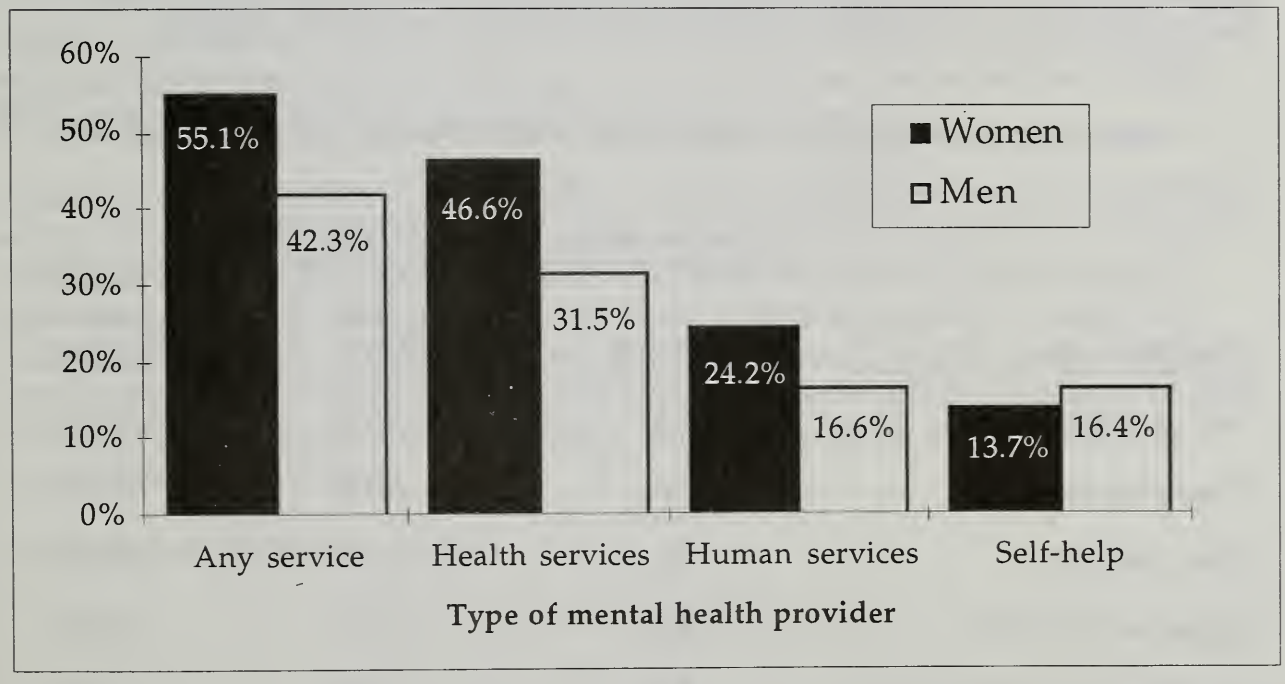


Figure 23: Percentage of people with mental disorders who sought treatment, by gender and type of mental health provider

Source: National Center for Health Statistics (1996).
Survey: National Comorbidity Survey, 1990-92

What is the extent of disability due to mental disorders?

The recent **National Health Interview Survey on Disability (NHIS-D)**, estimates the extent of disability associated with mental disorder, using four different definitions of disability. The first, **functional disability,** includes any serious symptoms of mental illness that severely interfered with life for the past year (as well as including limitations based on physical, sensory and other impairments). The second, **work disability**, is defined as a limitation in or inability to work as a result of physical, mental or emotional health conditions. **Perceived disability** refers to whether people consider themselves to have a disability or are considered by others to have one. Finally, disability program recipient includes anyone covered by **Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), special education** or related services and/or disability pensions (Adler, 1996; Kennedy, Carlson, Üstün, et al., 1997).

As shown below, the number of people with mental disorders who have a disability varies considerably depending on the disability definition. "Any disability" is an unduplicated count of people in the four other categories; by this measure, more than two-thirds (69.8%) of people with mental disorders have a disability. Using the concept of functional disability, 63.8% of people with mental disorders have a disability, while about one-third of people with mental disorders have a perceived disability (35.8%) or a work limitation (30.0%). Less than 20% of those with mental disorders are disability program recipients (18.3%).

More than two-thirds of people with mental disorders have a disability.

	People with mental disorders (23.5 million)		
Disability status	**# in millions**	**% of U.S. population**	**% of people with mental disorders**
Any disability	16.4	6.3%	69.8%
Functional disability	15.0	5.8%	63.8%
Work disability	6.1	2.3%	30.0%
Perceived disability	8.4	3.2%	35.8%
Disability program recipient	4.3	1.7%	18.3%

Table 6: Prevalence of disability among those with mental disorders

Sources: Adler (1996); Kennedy, Carlson, Üstün, et al. (1997).
Survey: NHIS-D, 1994-95

Are there gender differences in limitations due to serious mental illness?

Mental disorders, like physical disorders, can result in limitations in any major domain of a person's life, and people with mental disorders often experience an array of impairments in a number of domains. Characteristically, mental disorders are associated with limitations in the areas of work, social relationships, and self-care (Kennedy, Carlson, Üstün, et al., 1997). Unfortunately, the major national surveys tend not to measure limitations in social relationships, a domain that may be disproportionately impacted by mental disorders, compared to other disorders.

The most recent Mental Health Supplement to the **National Health Interview Survey (NHIS-MH)** conducted in 1989, illuminates the impact of serious mental illness on different areas of non-work-related functioning, and shows some gender differences. Among people between the ages of 25 and 64 who reported a **serious mental illness**, a large majority also reported disability (in the form of limitations in non-work-related activities). A higher percentage of men (87%) than women (71.3%) reported any non-work-related limitations. The most frequently reported limitation due to severe mental illness was a reduced ability to cope with daily stress (79.1% of men; 65.9% of women). More men (60%) than women (41.9%) reported that their mental illness interfered with their social functioning. Similarly, 59.2% of men with severe mental illness reported limitations in their ability to concentrate on tasks, compared to 41.4% of women. Finally more than a third (34.7%) of men, compared to only 16.9% of women reported limitations in their ability to perform **instrumental activities of daily living (IADLs)**, such as shopping and managing money.

A number of factors may be responsible for the lower rates of reported disability among women with severe mental illness. As noted previously, women and men have different prevalence rates for different psychiatric disorders, with women reporting more depressive and anxiety disorders and men reporting more substance abuse. These different disorders may differently impact daily functioning. As described earlier, women are also more likely than men to seek and receive treatment for mental illness, which may result in less disabling mental illness for women.

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Among those with serious mental illness, men are more likely than women to be limited in aspects of daily functioning by their illness.

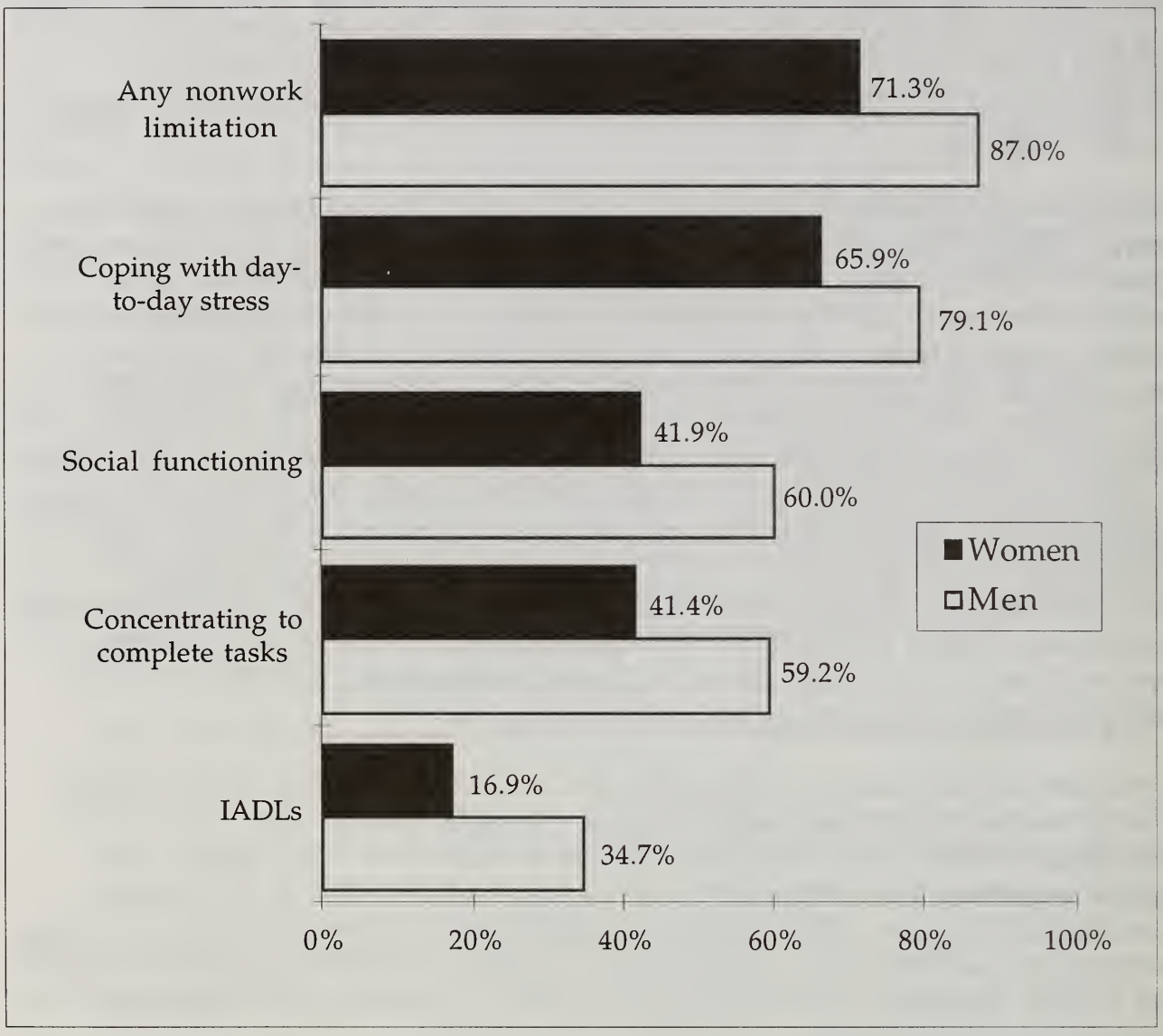

Figure 24: Percentage of people with severe mental illness reporting limitations in aspects of daily functioning, by gender

Source: National Center for Health Statistics (1996).
Survey: National Health Interview Survey, Mental Health Supplement (NHIS-MH), 1989

Section 6: Women, disability and aging

This section describes the rapidly growing population of elderly women with disabilities. Changes in birth and mortality rates have greatly increased the numbers of older people in this country, especially the numbers of elderly women. Disability-related effects of aging, including personal assistance needs, and rates of independent living, are discussed. As women age, they are more likely to become disabled by a number of medical conditions, compared to men. Some of those conditions that disproportionately cause disability among older women are also covered. Finally, caregiving as a women's issue is discussed.

Topic Questions

How do changes in women's life expectancies impact disability rates?

How does the need for personal assistance differ by age and gender?

How do age and gender influence the rate of multiple conditions?

What is the impact of arthritis on women?

How many women are at risk of disability related to osteoporosis?

Do women and men have different rates of independent living as they age?

Who provides care for elderly people with disabilities?

How do changes in women's life expectancies impact disability rates?

The average **life expectancy** for women has increased markedly in the past century, from 48.3 years in 1900 to 78.9 years in 1991. As shown below, the increase in life expectancy for older women has been especially dramatic in the second half of the century. In 1900, people who were 50 years old rarely lived to the age of 90. Even in 1950, only 10% of 50 year-old women could expect to survive to the age of 90. However, by 1990, nearly one-quarter of 50-year-old women could expect to live to the age of 90.

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Almost one out of every four women who were 50 years old in 1990 can expect to live to the age of 90.

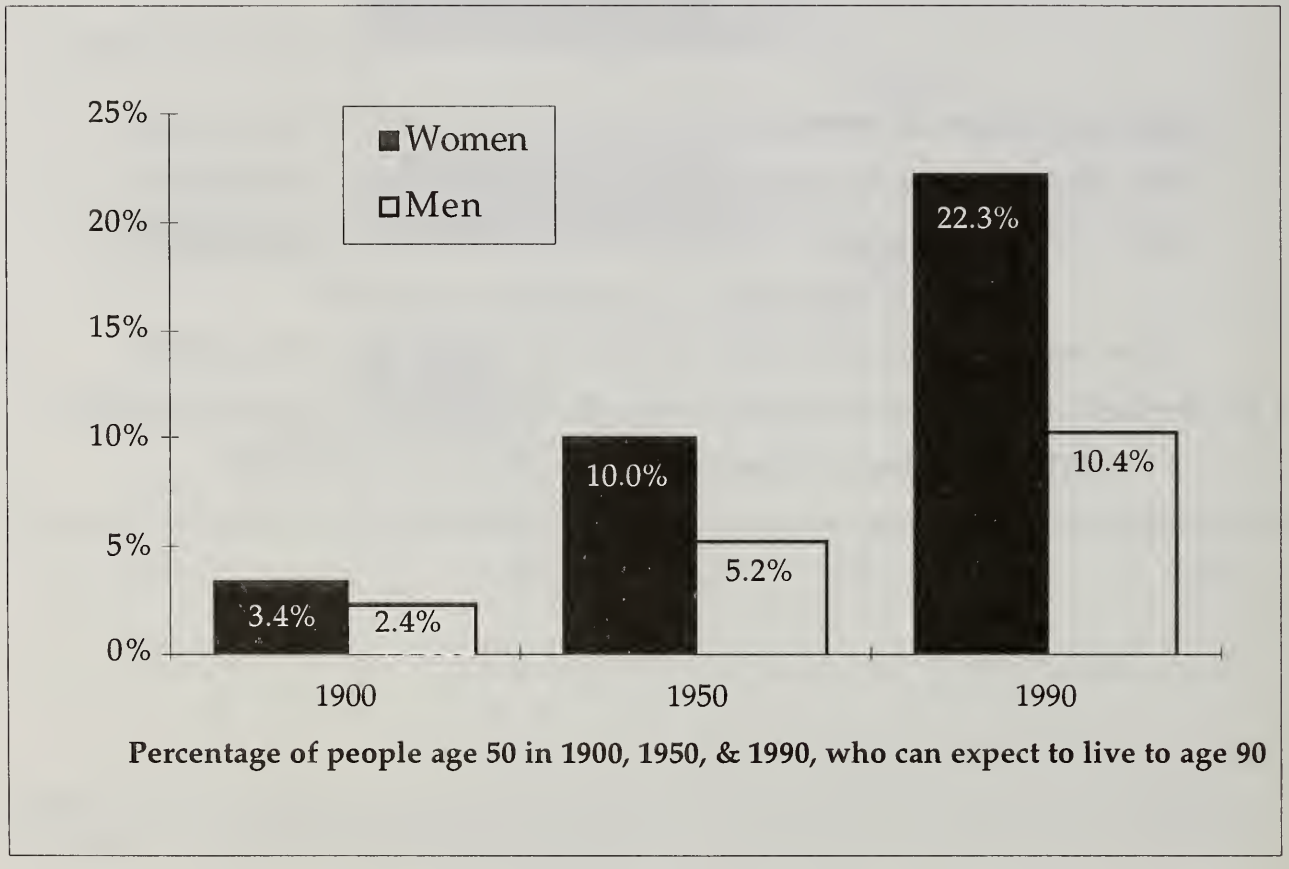

Figure 25: Percentage of women and men who were 50 years old in 1900, 1950, and 1990, who can expect to live to the age of 90

Source: Guralnik, et al. (1997).
Surveys: National Center for Health Statistics and U.S. Bureau of the Census, multiple surveys and multiple years

Changes in birth and mortality rates are leading to large increases in the population of older people, especially older women. By the year 2040, women 65 and older are projected to number 40.8 million, nearly nine times the number of women who were 65 and older in 1940. Even more striking is the fact that more than one in five of these elderly women will be 85 years of age or older, the group most likely to be disabled by **chronic health conditions**. Women live longer than men, but have more physical disability in each age group.

As discussed later in this section, these older women are less likely to be able to live independently and more likely to require personal assistance, compared to men in the same age group.

The population of elderly women is expected to increase dramatically by the year 2040.

Growth of the Older Population in the United States, 1940 to 2040

	Age 65 +				Age 85+			
	Women		Men		Women		Men	
year	n	% of all females	n	% of all males	n	% of women 65+	n	% of men 65+
1940	4,621,754	7.0	4,409,377	6.6	211,440	4.6	158,835	3.6
1960	9,132,912	10.0	7,542,119	8.4	573,802	6.3	366,252	4.9
1990	18,586,677	14.6	12,492,997	10.3	2,180,451	11.7	841,266	6.7
2020	29,443,000	17.9	23,776,000	15.0	4,319,000	14.7	2,141,000	9.0
2040	40,812,000	21.6	34,421,000	19.0	8,449,000	20.7	5,103,000	14.8

Table 7: Growth and estimated growth of the older population in the United States, 1940-2040

Source: Guralnik, et al. (1997); Day (1996)
Surveys: US Bureau of the Census, multiple years, and U.S. Bureau of the Census projections

How does the need for personal assistance differ by age and gender?

Overall, women are more likely than men to require **personal assistance** with one or more **activities of daily living** (ADLs) or **instrumental activities of daily living** (IADLs). Activities of daily living, basic self-maintenance activities that are essential for daily functioning, include bathing, dressing, eating, getting around inside the house, using the toilet and getting out of a bed or chair. Instrumental activities of daily living include going outside the home, keeping track of money, preparing meals, doing light housework and using the telephone. According to the **SIPP**, women account for 62.4% of people needing assistance with one or more ADLs or IADLs (McNeil, 1997). Results from the **NHIS**, shown in the chart below, also demonstrate that the likelihood of needing personal assistance with IADLs or ADLs increases markedly with age. Less than two percent of women 44 years and under need personal assistance, compared to nearly one-third (30.5%) of women 75 years and older.

Older women are most likely to need assistance with basic daily activities.

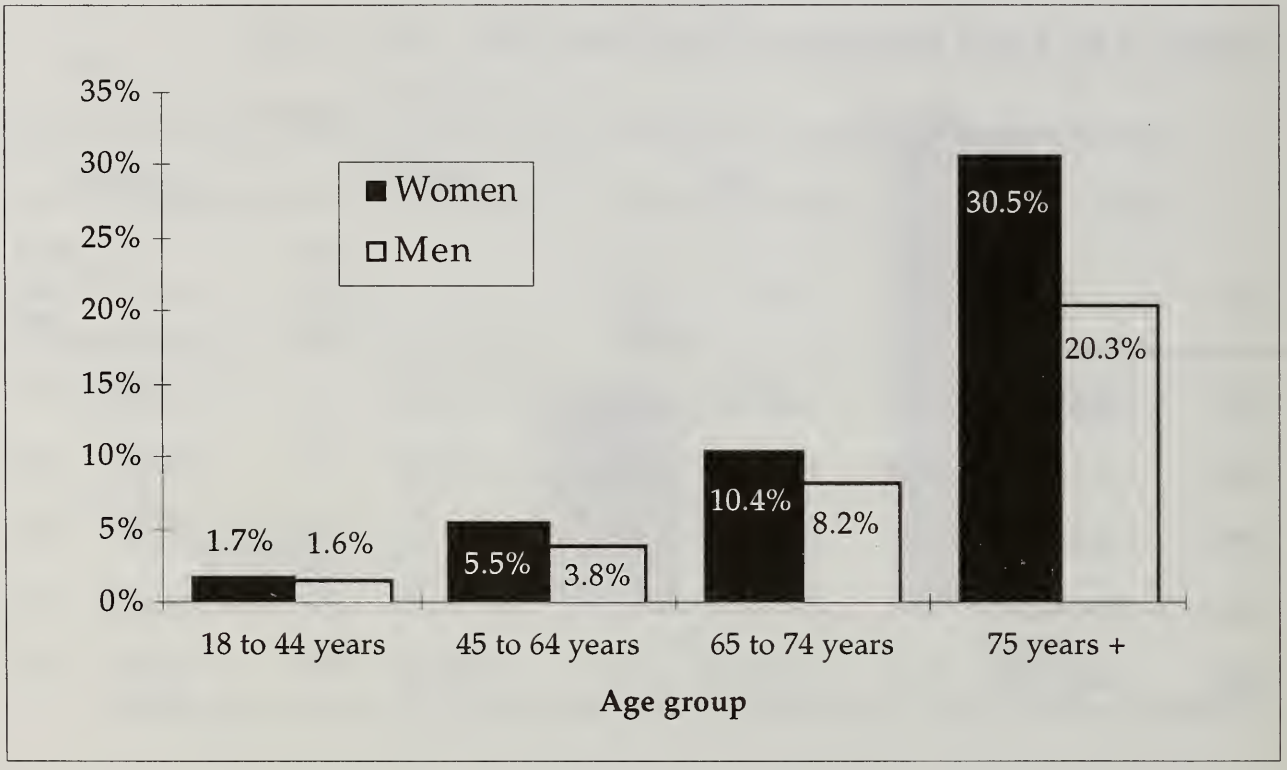

Figure 26: Percentage of people needing personal assistance with ADLs or IADLs, by age group and gender

Source: LaPlante & Carlson (1996).
Surveys: NHIS, 1992

How do age and gender influence the rate of multiple conditions?

Over forty percent of people with a **chronic health condition** experience other chronic conditions as well. **Comorbidity** (the technical term for having more than one chronic condition at the same time) puts people at greater risk for disability. As people age, they are much more likely to experience multiple chronic conditions.

Chronic conditions that are most strongly associated with disability among older adults include heart disease, arthritis (especially of the knees), hip fracture, diabetes, stroke, chronic obstructive pulmonary disease, visual impairment and cognitive impairment (Guralnik, et al., 1997). When more than one condition is present, the risk of disability is much greater.

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Comorbidity (the incidence of multiple conditions) increases with age.

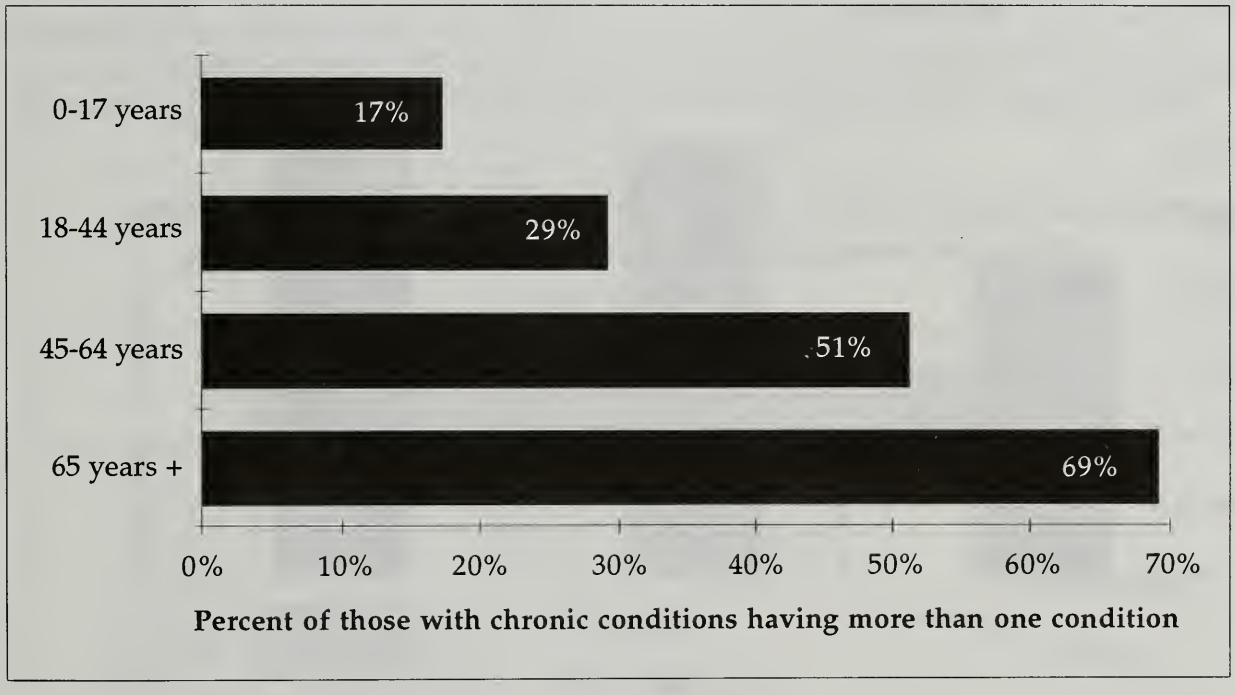

Figure 27: Percentage of those with chronic conditions who have more than one condition, by age group

Source: Hoffman & Rice (1996).
Survey: Estimates based on the 1987 National Medical Expenditures Survey

People with more than one chronic health condition go to the doctor more often, and are more likely to be hospitalized than those with one chronic condition. Due mainly to their greater longevity, older women have more comorbidities than older men.

Prevention of adverse outcomes of diseases is particularly important among people who have multiple conditions. These strategies include behavioral changes such as exercise programs, as well as the use of assistive technology. Equipment assistance, such as special aids and devices for accomplishing daily tasks, have been shown to be particularly effective in reducing functional impairment among elderly people with one or more chronic conditions (Verbrugge, et al., 1997).

Older women are more likely to experience multiple chronic conditions.

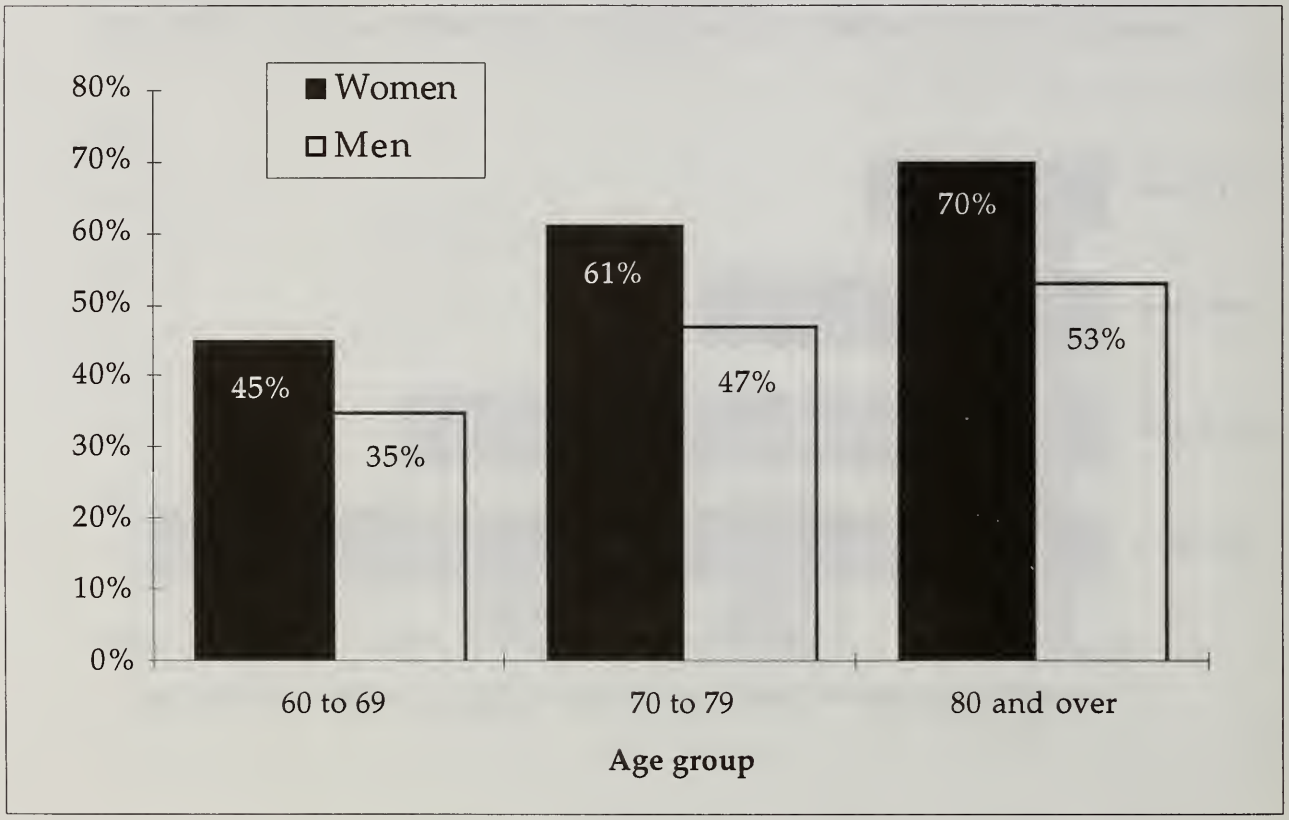

Figure 28: Percentage of people with more than one chronic condition, by gender

Sources: Hoffman & Rice (1996); Guralnik (1989).
Surveys: Estimates based on the 1987 National Medical Expenditures Survey

What is the impact of arthritis on women?

Arthritis is a leading cause of disability among working-age people, as well as a major cause of disability among people 65 years and older in the United States (Centers for Disease Control, 1994a, 1994b).

Arthritis affects women at a higher rate than men, due partly to women's greater longevity and the increasing **prevalence** of arthritis with age. However, even when estimates are age-adjusted to account for the fact that women live longer, women still experience higher prevalence of arthritis and higher rates of arthritis-related disability. Based on estimates from the 1989-1991 **NHIS**, the age-adjusted prevalence of arthritis among women 24 years and older is 17.1%, compared to 12.5% for men. The age-adjusted rate of activity limitations for women is 3.4%, compared to 2% for men (CDC, 1994a).

Among older women, arthritis is associated with worse perceived health status, and difficulty in performing physical activities. People with arthritis incur higher medical costs than their peers with no arthritis, particularly due to higher rates of **comorbidity** (other chronic conditions along with the arthritis). Women's rates of arthritis-related activity limitations are projected to increase as the average age of the population increases (Gabriel, 1996; Gabriel, Crowson & O'Fallon, 1995).

Women have higher rates of arthritis and related activity limitations, even after accounting for women's greater longevity.

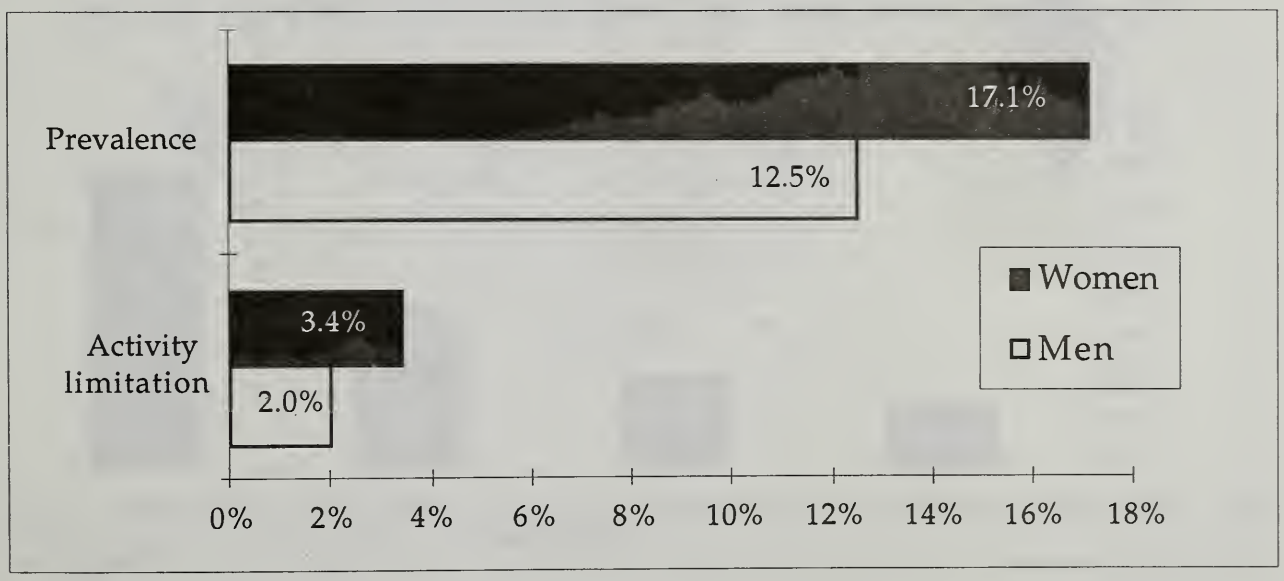

Figure 29: Age-adjusted prevalence and activity limitation due to arthritis, by gender

Source: Centers for Disease Control (1994a & 1994b)
Survey: NHIS, 1989-1991

How many women are at risk of disability related to osteoporosis?

Osteoporosis (very low bone density) affects women 2 to 3 times more often than men. Currently, 26 million American women are at risk for bone fractures as a result of osteoporosis (Gabriel, 1996). As illustrated below, the **prevalence** of osteoporosis in women increases sharply with age. Based on extrapolation from an age-stratified sample of women in Rochester, MN, it is estimated that 30% of post-menopausal White women in the United States have osteoporosis of the spine, hip, or arm. Women 80 and over have an estimated prevalence rate of 70%, more than 4 times the rate for women in their 50's (Melton, 1997). Asian-American and White women have comparable prevalence rates; African-American women are 2 to 3 times less likely to suffer osteoporotic fractures.

It is estimated that one-third of women will suffer hip fractures in their late 70's to early 80's. At least 19% of hip fracture patients require long-term nursing care. As the population ages, the adverse effects of osteoporosis are also likely to increase; the current rate of approximately 250,000 hip fractures per year is expected to triple by the year 2040 (Bockman, 1997).

In the **National Study of Women with Physical Disabilities**, the Center for Research on Women with Disabilities found that younger women with disabilities had seven times the rate of osteoporosis as women without disabilities. This may be due to lower rates of weight-bearing exercise or other factors not yet understood (Nosek, Howland, & Rintal, et al., 1997).

Osteoporosis affects more than two-thirds of women 80 years and over.

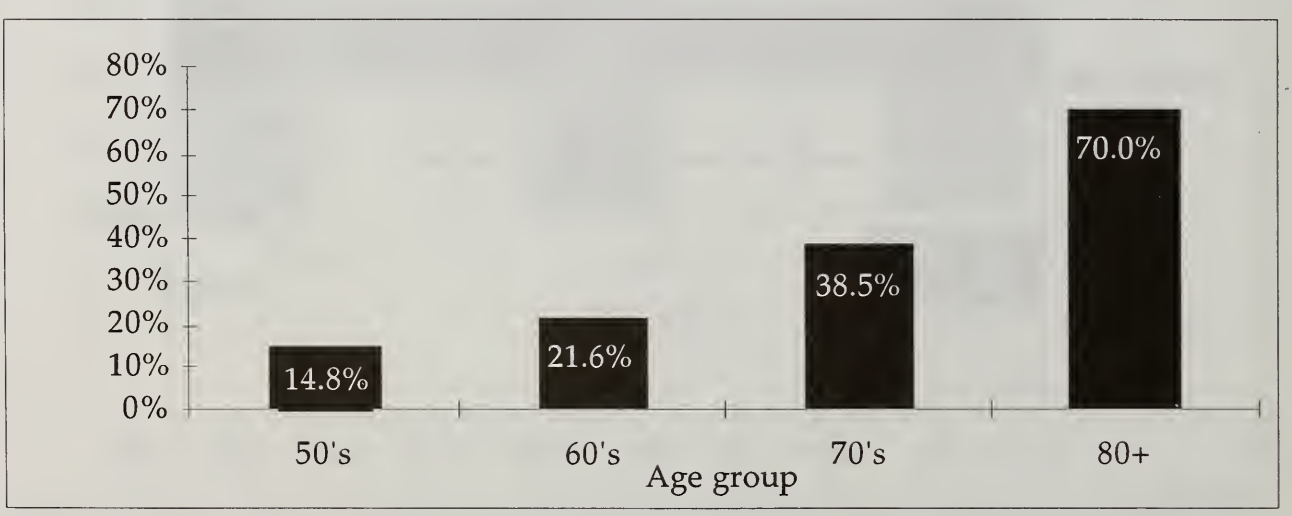

Figure 30: Percentage of women over 50 with osteoporosis, by age group

Sources: Bockman (1997); Melton (1997).
Survey: Rochester Epidemiology Project, multiple years

Do women and men have different rates of independent living as they age?

As people age, they are often less able to live independently. The chart below shows the percentage of the population 65 and over, by age group and gender, that (1) lives at home independently, (2) lives at home but requires assistance, or (3) resides in a nursing home. Overall, older women are more likely than older men to require assistance at home. They are also more likely to live in a nursing home. In the 65-74 year old group, there are few differences between women and men, but the differences increase steeply as age increases. Among people over 85, only 45% of women live independently, compared to 63% of men.

Compared to men, older women are less likely to live independently and more likely to live in a nursing home or need assistance at home.

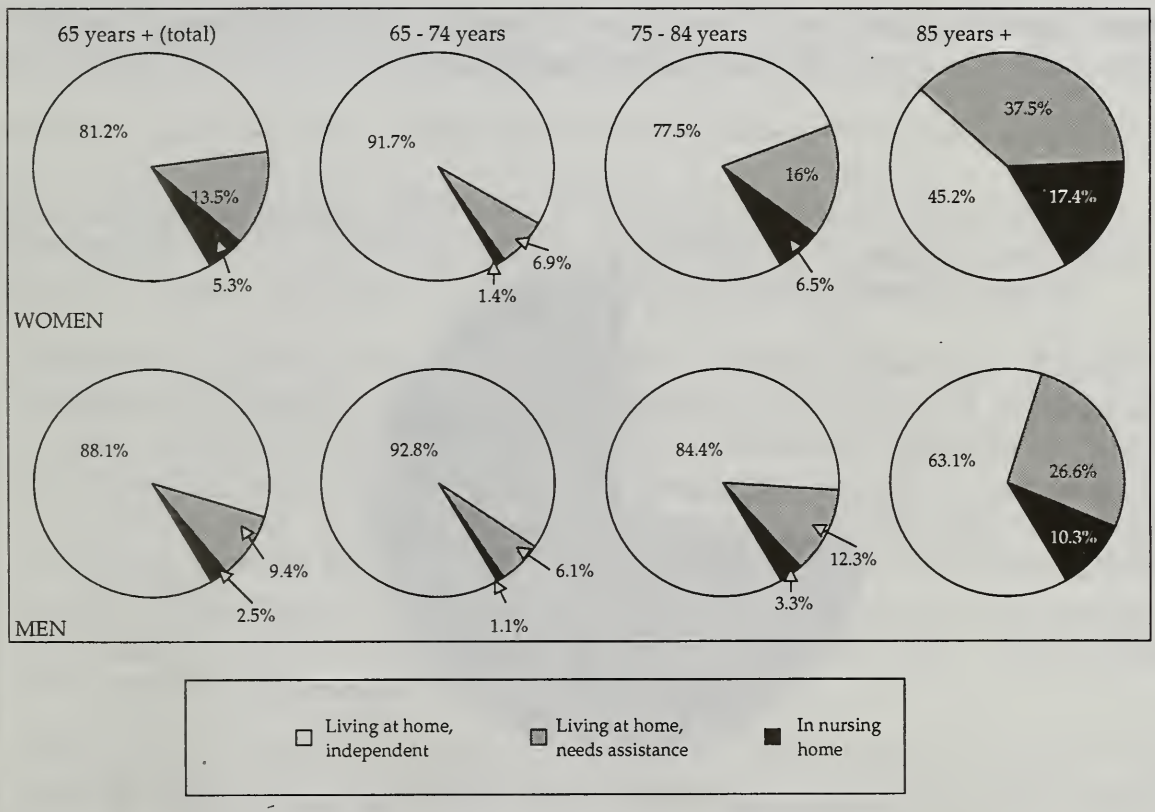

Figure 31: Living arrangement status of women and men 65 years and older, by age group

Source: Guralnik (1997).
Surveys: National Nursing Home Survey, 1995; NHIS-D, 1994.

Who provides care for elderly people with disabilities?

Disability and aging are women's issues, not only because women are more likely to become disabled as they grow older, but because women provide most of the informal (unpaid) caregiving for people with disabilities.

In 1996, 15% of adults were estimated to be providing care to family members who were seriously ill or had a disability. From 1987 to 1996, the number of households that provide informal care to adults over 50 more than tripled, from 7 million to 22.4 million (National Alliance for Caregiving, 1997). Women have consistently been the primary caregivers. In surveys conducted in 1982 and 1996, approximately three-quarters of these informal caregivers were women (Hoffman & Rice, 1996; House of Representatives Select Committee on Aging, 1988; National Alliance for Caregiving, 1997).

Women represent three out of every four caregivers for older people with chronic health conditions.

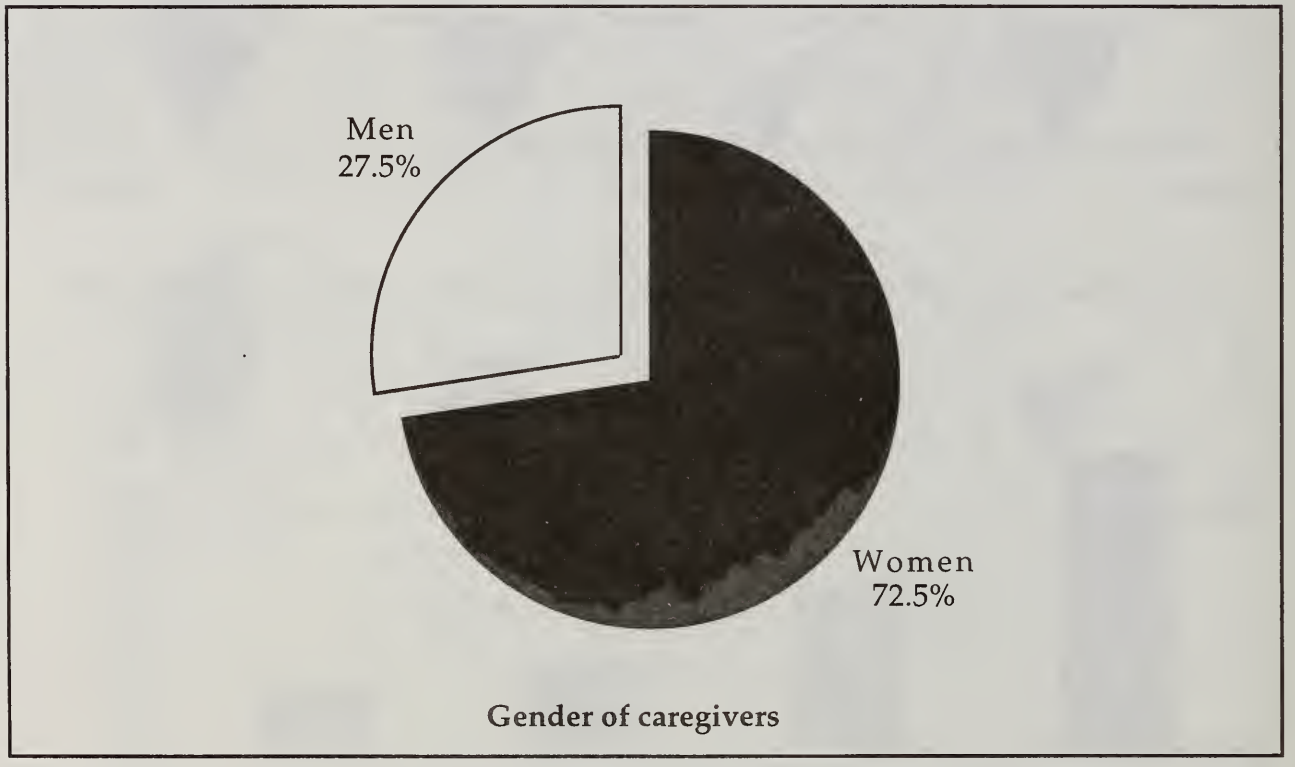

Figure 32: Gender of people who provide care to older people with chronic health conditions

Source: National Alliance for Caregiving (1997)
Survey: National Alliance for Caregiving Survey, 1996

Section 7: Research Gaps and Topics for Further Investigation

This chartbook presents statistical information on women and girls with disability, based primarily on large national-level surveys. Other research studies have been conducted on the topics of gender and disability that are not included in the chartbook because they cannot be generalized to the national level. Until quite recently, research on disability focused more on commonalities among people with disability, rather than addressing gender-related differences (Fine & Asch, 1988). As a result, less is known about the unique characteristics and experiences of girls and women with disability. Clearly, the information presented here only begins to investigate issues of gender and disability. The material presented in this chartbook makes it clear that there is still much research to be done, and that there are many challenges facing women and girls with disabilities. These findings point to the need for more policy attention to the needs of girls and women who have a disability.

Below, we give examples of some of the gaps in research on girls and women with disabilities that are suggested by the chartbook findings and other studies.

Girls and young women: Relatively little has been written about the characteristics and experiences of girls and young women with disabilities. The chartbook raises a number of questions needing further investigation.

- Many fewer girls than boys receive **special education** services. It is not known whether this discrepancy is due to different prevalence rates or other eligibility factors. Are there girls who could profit from special education services who are being left out? Compared to boys, girls graduating from special education have lower rates of employment and post secondary training and education. In the most recent report to Congress on special education, these and other gender differences were mentioned as important topics needing further investigation (U.S. Department of Education, OSERS, 1998). We echo that recommendation.

- What are the reasons why girls receive **SSI** at lower rates than boys? The barriers that prevent girls with disabilities from receiving benefits must be identified. How can these disparities be remediated?

- Data presented in this chartbook indicate that women are less frequently represented in computer-related occupations. What can be done to prepare young women with disabilities for science, math and technology-related careers?

Adulthood: Gender inequalities in work, income, and benefits are central issues facing women with disabilities. The chartbook raises a number of research questions about women with disabilities and their participation in the labor force that must be answered with further research.

- Women with disabilities are doubly disadvantaged in the workplace, with lower labor force participation and lower income than other women as well as men with and without disabilities. How can these inequalities be remedied?

- Increased attention must be paid to the work patterns of women with disabilities over the life course and the relationship of those patterns to employment opportunities, income levels and related benefits.

- Is there a relationship between health, well-being and labor-force participation for women with disabilities?

- Chartbook findings reveal that fewer women than men receive services from Vocational Rehabilitation. Other writers have suggested that rehabilitation counselors may present different career paths to disabled women and men with similar aptitudes (Fine & Asch, 1988). Research is needed to investigate gender differences and suggest solutions to inequities.

Adult women with disabilities also face non-work-related challenges. The chartbook raises a number of research questions about other kinds of issues faced by women with disabilities during middle adulthood.

- Data show that women with activity limitations are less likely to be married and more likely to be widowed than other women and men with and without disabilities. This finding, however, is probably related to women's greater longevity. National survey research is needed to investigate patterns of family formation among younger women with disabilities, as well as to better understand the relationship between disability and widowhood in later life.

- National-level findings presented in the chartbook on screening for breast and cervical cancer need further investigation. For example, a study in a general community sample (Nosek & Howland, 1997) found that women with disabilities receive pelvic exams less frequently than women with no disabilities. The study concludes that future research on access to health care by women with disabilities should focus on women with low levels of education or income and those who are of minority status.

- A study conducted by the Center for Research on Women with Physical Disabilities suggests that women with disabilities may be more vulnerable to certain kinds of physical, sexual or emotional abuse than their peers with no disability (Nosek, Howland, Rintal, et al., 1997; Nosek, Howland, & Young, 1997; Young, Nosek, Howland, et al., 1997). The study, conducted in a community sample, found that women with physical disabilities experienced

abuse for longer periods, were subject to withholding of needed equipment, medication or transportation, and were more likely to be abused by health care providers, attendants or strangers. Nationally representative survey research is needed to investigate these issues. What can be done to prevent abuse of women with disabilities and eliminate barriers to accessing abuse services? How are certain subgroups, such as women with developmental disabilities and mental illness affected by violence and abuse and what kinds of services would help?

- Data from the National Resource Center on Parents with Disabilities at Through the Looking Glass raises questions about parents with disabilities. What are the implications of omitting parenting from activities of daily living, particularly with regard to receiving personal assistance services? Public policy mechanisms for changing inequities must be identified.

Aging: Women, including those with disabilities, are living longer and healthier lives. However, older women with disabilities continue to face threats to their independence, multiple health conditions, increased health care needs and high medical expenses. The following questions represent some of the needs for research on older women with disabilities that are suggested by the research presented in this chartbook and by other studies on elderly women with disabilities:

- There is a particular need for studies of pain and coping with pain among older women. Studies estimate that 25% to 50% of community-dwelling older adults report chronic pain. The prevalence of pain among nursing home residents, mainly women, is estimated at 45% to 80% (Roberto, 1997). Future research, particularly longitudinal research, is needed to better understand the development of chronic pain among older women with disabilities. Research is also needed to improve the quality of life for older women with disabilities who experience pain.

- Women, including women with disabilities, frequently care for spouses or older relatives when they develop a chronic illness or disability. It is not known how many women with disabilities are themselves caregivers to other adults. Research is needed on this topic.

- The older population in this country is expected to become more ethnically diverse in the next 20 years, with particular growth among elder Hispanic and Asian-Americans (Wetle, 1997). Especially needed are studies on older women with disabilities, focusing on the special needs of minority women.

- In general, research is needed to identify services and resources for helping older women with disabilities to age in a way that maintains maximum health and independence.

Many important issues in gender and disability are relevant to girls and women across the entire lifecycle. Research from the Center on Emergent Disability suggests that women, given their higher rates of poverty, are disproportionately represented among emerging disabilities due to domestic violence, inadequate prenatal care, adolescent pregnancy, poor nutrition, and other factors (Center on Emergent Disability, 1997). Barriers to medical care also affect females with disability at all ages. More research is needed on availability, use and quality of health care for girls and women with disabilities. Research on minority girls and women with disabilities is especially vital as the population of the United States becomes more ethnically diverse. Many questions raised in the chartbook are left unanswered. We hope that the identification of gaps in knowledge will encourage research and public policy changes to address these issues that affect girls and women with disabilities across the life cycle.

Data Tables

Figure 1: Americans with and without disability, by gender (Source: McNeil, 1997/Survey: SIPP, 1994-95)

		Females		Males	
	Population	**No disability**	**With disability**	**No disability**	**With disability**
# (in millions)	261.7	105.3	28.6	102.6	25.3
% of total population	100%	40.2%	10.9%	39.2%	9.7%
% of gender group	-	78.7%	21.3%	80.2%	19.8%

Figure 2: Percentage with activity limitation, by age group and gender (Source: LaPlante & Carlson, 1996/Survey: NHIS, 1992]

Age group	**Females**	**Males**
Under 18	5.0%	7.1%
18 - 64	14.4%	13.8%
65 - 84	36.7%	37.6%
85 and over	59.3%	50.2%
Total	15.4%	14.6%

Figure 3: Injury rate per 100 population, by gender (Source: U.S. Bureau of the Census, 1995/Survey: NHIS, 1983-1993)

Year	**Females**	**Males**
1983	23.7	29.8
1984	22.9	30.1
1985	23.1	30.6
1986	23.3	29.8
1987	23.1	29.1
1988	21.6	27.7

Year	Females	Males
1989	20.9	26.9
1990	21.0	28.1
1991	21.5	26.7
1992	20.7	26.8
1993	22.0	27.0

Figure 4: Number of disability days lost annually, per person, by gender (Source: U.S. Bureau of the Census, 1997/Survey: NHIS, 1994)

	Females	Males
Bed-disability days	7.4	4.9
Work-loss days	5.9	4.6
School-loss days	5.0	4.1
Total restricted activity days	18.2	13.6

Figure 5: Percentage with disability, by ethnicity and gender (Sources: Bradsher, 1995; McNeil, 1993/Survey: SIPP, 1991-92)

Ethnicity	Females	Males
White	20.3%	19.1%
Black	21.7%	18.0%
Native American	21.8%	21.9%
Asian	10.7%	9.1%
Hispanic	16.2%	14.3%

Figure 6: Disability rates for children and youth (0 to 21 years old) by age group and gender (Source: McNeil, 1997/Survey: SIPP, 1994-95)

Age Group	Females	Males
Less than 3 years	1.9%	3.3%
3 to 5 years	3.5%	6.9%
6 to 14 years	9.6%	15.8%

Age Group	Females	Males
15 to 21 years	10.8%	13.4%
Total: 0 to 21 years	8.0%	12.0%

Figure 7: Activity-limiting main conditions with highest prevalence for children under 18, by gender (Source: LaPlante & Carlson, 1996/Survey: NHIS, 1992)

Condition	Girls	Boys
Respiratory diseases (mainly asthma)	24.8%	26.3%
Mental retardation	16.9%	17.9%
Mental disorders	6.1%	11.7%
Speech impairments	4.7%	7.5%
Nervous system diseases	4.9%	2.8%
Hearing impairments	4.0%	2.5%
Orthopedic impairments	4.5%	1.7%

Figure 8: Children and youth (0 to 21 years old) in special education, as percentage of total public school enrollment, by disability type (Sources: U.S. Department of Education, OSERS, 1996 and National Center for Education Statistics, 1997/Survey: Office of Special Education data, 1977-1995)

Year	1977	1979	1981	1983	1985	1987	1989	1991	1993	1995
All disabilities	8.3%	9.1%	10.1%	10.8%	11.0%	11.0%	11.3%	11.6%	12.0%	12.2%
Specific learning disabilities	1.8%	2.7%	3.6%	4.4%	4.7%	4.8%	4.9%	5.2%	5.5%	5.6%
Speech/ language impairments	2.9%	2.9%	2.9%	2.9%	2.9%	2.9%	2.4%	2.4%	2.3%	2.3%
Mental retardation	2.2%	2.1%	2.0%	1.9%	1.8%	1.6%	1.4%	1.3%	1.2%	1.2%

Year	1977	1979	1981	1983	1985	1987	1989	1991	1993	1995
Serious emotional disturbance	0.6%	0.7%	0.8%	0.9%	0.9%	1.0%	0.9%	0.9%	0.9%	1.0%

Figure 9: Percentage enrolled in special education, by gender and disability type (Sources: U.S. Dept of Education, OSERS, 1998; Valdes et al., 1990/Survey: U.S. Department of Education, Office of Special Education Programs, Data Analysis System)

Disability	Girls	Boys
Learning disability	26.6%	73.4%
Emotional disturbance	23.6%	76.4%
Speech impairment	40.5%	59.5%
Mental retardation	42.0%	58.0%
Visual impairment	44.4%	55.6%
Hearing impairment	48.0%	52.0%
Deafness	45.5%	54.5%
Orthopedic impairment	45.8%	54.2%
Multiple disabilities	34.6%	65.4%
Deaf-blindness	50.5%	49.5%

Figure 10: Number (in thousands) of blind and disabled children (0 to 17 years old) receiving SSI, by gender (Source: Social Security Administration, 1988-1997/Survey: Social Security Administration Program Data, 1987-1996)

Year	Girls	Boys
1988	124.0	168.5
1989	122.4	172.6
1990	136.7	197.9
1991	164.3	249.9
1992	226.7	361.7
1993	288.7	477.5
1994	325.9	559.0

Year	Girls	Boys
1995	329.2	583.7
1996	339.6	602.6
1997	326.3	553.5
1998	323.4	561.8

Figure 11: Percentage with job or business, by disability status and gender, 21 to 64 years old (Source: McNeil, 1997/Survey: SIPP, 1994-95)

Disability status	Women	Men
No disability	74.5%	89.8%
Non-severe disability	68.4%	85.1%
Severe disability	24.7%	27.8%

Figure 12: Number and percentage of people with and without disabilities in computer-related job categories, by gender, 16 to 64 years old (Source: J. McNeil, personal communication, January, 1999/Survey: SIPP, 1994-95, unpublished data)

(Percentage in gender group is shown in parentheses)

	Women		Men	
	No disability	With disability	No disability	With disability
Mathematical and computer scientists	255,000 (83.2%)	51,400 (16.8%)	713,700 (92.5%)	58,000 (7.5%)
Computer programmers	156,800 (94.4%)	9,300 (5.6%)	394,500 (89.7%)	45,400 (10.3%)
Computer equipment operators	316,100 (91.7%)	28,700 (8.3%)	241,800 (85.8%)	40,000 (142%)

Figure 13: Percentage participating in labor force, by work disability status and gender, 16 to 64 years old (Source: U.S. Bureau of the Census Website/Survey: CPS, 1998)

Disability status	Women	Men
No work disability	75.8%	89.1%
Work disability	28.5%	32.3%

Figure 14: Median monthly earnings, by disability status and gender, 21 to 64 years old (Source: McNeil, 1997/Survey: SIPP, 1994-95)

Disability status	Women	Men
No disability	$1,470	$2,190
Non-severe disability	$1,200	$1,857
Severe disability	$1,000	$1,262

Figure 15: Percentage of people living below poverty level, by work disability status and gender, 16 to 64 years old (Source: U.S. Bureau of the Census, 1993/Survey: CPS, 1992)

Disability status	Women	Men
No work disability	12.1%	8.1%
Work disability	33.8%	24.2%
Severe work disability	40.5%	31.2%

Figure 16: Percentage of people with work disability participating in assistance programs, by gender (Source: U.S. Bureau of the Census, 1997/Survey: CPS, 1995)

Assistance program	Women	Men
Social Security	25.6%	30.6%
Food stamps	29.1%	19.8%
Medicaid	36.2%	27.2%
Public housing	6.8%	4.4%
Subsidized housing	4.6%	2.7%

Figure 17: Average monthly Social Security benefit for disabled workers, by gender, in five-year increments (Source: Social Security Administration, 1997/Survey: Social Security Administration Program Data, 1960-1995)

Year	Women	Men
1960	$77	$93
1965	$85	$102
1970	$113	$139
1975	$185	$244
1980	$296	$407
1985	$381	$534
1990	$464	$652
1995	$555	$762

Figure 18: Number of Vocational Rehabilitation cases closed, by type of closure and gender (Source: Rehabilitation Services Administration Program Data, FY1996)

Type of closure	Women	Men
With employment outcome	96,319	117,471
Not eligible	57,866	73,309
No employment outcome	101,828	135,776

Figure 19: Marital status, by activity limitation status and gender, 18 years and older (Source: LaPlante & Carlson, 1996/Survey: NHIS, 1992)

(Numbers in 1000's)	Men		Women	
Marital status	No activity limitation	With activity limitation	No activity limitation	With activity limitation
Never married	16,344	2,383	13,681	1,990
Divorced or separated	4,996	1,608	8,214	2,634
Widowed	1,237	872	6,461	4,553
Married	49,758	10,428	49,584	9,067

Figure 20: Percentage of adults with children under 18 years old in home, by disability status and gender (Source: Toms-Barker & Maralani, 1997/Survey: SIPP, 1993)

Disability status	Women	Men
No disability	45%	35%
With disability	33%	26%
With severe disability	31%	18%

Figure 21: Per capita medical expenditures, by age group, activity limitation status, and gender (Source: Trupin, Rice, & Max, 1995/Survey: National Medical Expenditures Survey, 1987, with data updated to 1993)

	No activity limitation		With activity limitation	
Age group	Females	Males	Females	Males
1 to 17	$734	$620	$1,670	$1,650
18 to 44	$1,217	$734	$2,938	$3,425
45 to 64	$1,324	$1,371	$4,365	$6,100
65+	$2,066	$2,640	$6,226	$6,525

Figure 22: Lifetime prevalence of certain types of psychiatric disorders, by gender (Sources: National Center for Health Statistics, 1996; Kessler, McGonagle, Zhao, et al., 1994/Survey: National Comorbidity Survey, 1990-92)

Type of disorder	Women	Men
Any	47.3%	48.7%
Depressive	23.9%	14.7%
Anxiety	30.5%	19.2%
Substance use	17.9%	35.4%

Figure 23: Percentage of people with mental disorders who sought treatment, by gender and type of mental health provider (Source: National Center for Health Statistics, 1996/Survey: National Comorbidity Survey, 1990-92)

Type of mental health provider	Women	Men
Any service	55.1%	42.3%
Health services	46.6%	31.5%
Human services	24.2%	16.6%
Self-help	13.7%	16.4%

Figure 24: Percentage of people with severe mental illness reporting limitations in aspects of daily functioning, by gender (Source: National Center for Health Statistics, 1996/Survey: NHIS, Mental Health Supplement, 1989)

Type of limitation	Women	Men
Any non-work limitation	71.3%	87.0%
Coping with day-to-day stress	65.9%	79.1%
Social functioning	41.9%	60.0%
Concentrating to complete tasks	41.4%	59.2%
IADLs	16.9%	34.7%

Figure 25: Percentage of women and men who were 50 years old in 1990, 1950, and 1990, who can expect to live to the age of 90 (Source: Guralnik, et al., 1997/Survey: Census and Census projections, multiple years)

Year	Women	Men
1900	3.4%	2.4%
1950	10.0%	5.2%
1990	22.3%	10.4%

Figure 26: Percentage of people needing personal assistance with ADLs or IADLs, by age group and gender (Source: LaPlante & Carlson, 1996/Survey: NHIS, 1992)

Age group	Women	Men
18 to 44	1.7%	1.6%
45 to 64	5.5%	3.8%
65 to 74	10.4%	8.2%
75 & older	30.5%	20.3%

Figure 27: Percentage of those with chronic conditions who have more than one condition, by age group (Source: Hoffman & Rice, 1996/Survey: National Medical Expenditures Survey, 1987)

Age group	Percentage with more than one condition
0-17 years	17%
18-44 years	29%
45-64 years	51%
65 years +	69%

Figure 28: Percentage of people with more than one chronic condition, by gender (Sources: Hoffman & Rice, 1996/Guralnik, 1989/Survey: National Medical Expenditures Survey, 1987)

Age	Women	Men
60 to 69	45%	35%
70 to 79	61%	47%
80 and over	70%	53%

Figure 29: Age-adjusted prevalence and activity limitation due to arthritis, by gender (Source: Centers for Disease Control, 1994a, 1994b/Survey: NHIS, 1989-91)

	Women	Men
Activity limitation	3.4%	2.0%
Prevalence	17.1%	12.5%

Figure 30: Percentage of women over 50 with osteoporosis, by age group (Source: Bockman, 1997; Melton, 1997/Survey: Rochester Epidemiology Project, multiple years)

Age group	Percentage with osteoporosis of spine, hip or arm
50's	14.8%
60's	21.6%
70's	38.5%
80+	70.0%

Figure 31: Living arrangement status of women and men 65 years and older, by age group (Source: Guralnik, 1997/Surveys: National Nursing Home Survey, 1995; NHIS-D, 1994)

	Women			Men		
Age group	At home, independent	At home, needs assistance	In nursing home	At home, independent	At home, needs assistance	In nursing home
65+ (total)	81.2%	13.5%	5.3%	88.1%	9.4%	2.5%
65-74	91.7%	6.9%	1.4%	92.8%	6.1%	1.1%
75-84	77.5%	16.0%	6.5%	84.4%	12.3%	3.3%
85 +	45.2%	37.5%	17.4%	63.1%	26.6%	10.3%

Figure 32: Gender of people who provide care to older people with chronic health conditions (Source: National Alliance for Caregiving, 1997/Survey: National Alliance for Caregiving Survey, 1996)

Gender of caregiver	**Percentage**
Women	72.5%
Men	27.5%

Glossary

This alphabetical list provides an explanation of terms that may require clarification. The definitions are taken from original surveys or cited publications as closely as possible, to convey the original authors' perspectives. Surveys that are mentioned in this Glossary are explained in more detail in the Appendix.

ADL: See **Activities of daily living (ADLs).**

Activities of daily living (ADLs): The **National Health Interview Survey (NHIS)** asks questions to identify people who "need the help of other persons with personal care needs such as eating, bathing, dressing or getting around...(inside the) home." (Adams & Marano, 1995). These particular activities are termed activities of daily living.

The **Survey of Income and Program Participation (SIPP)** definition of ADL includes eating, bathing, dressing or getting around inside the home, but also specifies getting into and out of bed or a chair, and toileting. The SIPP asks about whether a person has difficulty with any of these ADLs (one of the criteria for **disability**) and whether a person needs assistance to do the activity (one of the criteria for **severe disability**).

The **National Medical Expenditures Survey (NMES)** definition is similar to the SIPP definition. The NMES describes ADLs as basic self-care tasks that include bathing, dressing, toileting, getting in and out of bed or a chair, feeding oneself, and walking across the room. A limitation in an ADL is defined as needing the help of another person or special equipment to perform the activity.

(See also **instrumental activities of daily living**.)

Activity limitation(s): On the **National Health Interview Survey (NHIS),** activity limitation refers to a long-term reduction in a person's capacity to perform the average kind or amount of activities associated with his or her age group. (See **major activity** for an explanation of the activities associated with each age group.) People are classified into one of four categories: (1) unable to perform the major activity, (2) able to perform the major activity but limited in the kind or amount of this activity, (3) not limited in the major activity but limited in the kind or amount of other activities, and (4) not limited in any way. The NHIS classifies people as limited (groups 1-3) or not limited (group 4). People are not classified as limited in activity unless one or more chronic health conditions are reported as the cause of the activity limitation. (See also **chronic health condition**.)

The **National Medical Expenditures Survey (NMES)** considers adults 18 years and over to have an activity limitation if their health keeps them from working at a job, doing work around the house, or going to school or they are unable to do certain kinds or amounts of work, housework, or school work because of their health. For school-aged children between the ages of 5 and 17, activity limitations are defined by questions about attending or needing special schools or classes, and/or limitations in school or other activities because of an impairment or health problem. For young children under 5 years, activity limitation is defined by questions about limitation in play or other activities, due to an impairment or health problem.

Bed-disability days: From the **NHIS**, a bed-disability day is one during which a person stayed in bed for more than half a day because of illness or injury. Bed-disability days include **work-loss** and **school-loss days** actually spent in bed. Bed-disability days measure the effect of brief episodes of illness or injury as well as long-term or chronic disability.

CPS: See **Current Population Survey** in the Appendix for survey description.

Children with disabilities: The Individuals with Disabilities Education Act (**IDEA**) includes children with mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities. In order to qualify under IDEA, children must need **special education** and related services by reason of their disability.

Chronic health condition/chronic condition: On the **NHIS**, a condition that a respondent described as having persisted for three or more months is considered to be chronic. Other conditions are always classified as chronic no matter how long the person has had the condition.

For analyses based on the **NMES**, the term "chronic condition" is a general term that encompasses both chronic illness (the presence of long-term disease or symptoms, usually lasting three months or more) and chronic impairment (a physiological, psychological, or anatomical abnormality of bodily structure or function, including all losses or abnormalities, not just those attributable to active pathology).

Comorbidity: Comorbidity is the technical term for having more than one chronic condition or disorder at the same time.

Current Population Survey (CPS): See Appendix for survey description.

Diagnostic and Statistical Manual (DSM-III, DSM-III-R and DSM-IV): The Diagnostic and Statistical Manual classifies and describes mental disorders and their symptoms. Many current studies of mental illness and disability use DSM diagnoses to define the mental disorders.

Disabled worker: Under the Social Security definition, disabled workers are people under age 65 who receive benefits as part of the **Old Age, Survivors and Disability Insurance (OASDI)** program. They have been determined to be disabled under Social Security criteria (i.e., cannot engage in "substantial gainful activity.") They have also earned at least a certain minimum amount of wages in employment covered under Social Security in order to receive income from **Social Security Disability Insurance (SSDI).**

Disability: On the **NHIS**, disability refers to any long- or short-term reduction of a person's activity as a result of an acute or chronic condition.

On the **SIPP**, people age 15 and over were considered to have a disability if they met any of the following criteria: (1) used a wheelchair; (2) had used a cane or similar aid for 6 months or longer; (3) had difficulty with a functional activity; (4) had difficulty with one or more **activities of daily living (ADLs)**; (5) had difficulty with one or more **instrumental activities of daily living (IADLs)**; or (6) were identified as having a developmental disability or a mental or emotional disability. A person also was considered to have a disability if (7) the person was 16 years and over and had a condition that made it difficult to do housework; (8) the person was between 16 and 67 years of age and had a condition that limited the amount or kind of work the person could do at a job; (9) the person was under 21 years of age and his or her parents responded on the survey about receipt of developmental services or reported limitations in usual activities, the ability to do regular school work or the ability to walk, run, or use stairs; or (10) the person was under age 65 and covered by Medicare or received SSI.

Epidemiological Catchment Area (ECA) Survey: See Appendix for survey description.

ESEA: ESEA refers to the Elementary and Secondary Education Act, State Operated Programs, Chapter 1. Until 1995, ESEA was one of two major programs that provided states with financial assistance to educate school-age children and youth with disabilities. Now all federal assistance is provided under **IDEA**.

Functional activity or activities: The **SIPP** asked respondents about their ability to perform the following specific sensory and physical activities: (1) seeing ordinary newspaper print (with glasses or contacts if normally used), (2) hearing normal conversation (using hearing aid if normally used), (3) having speech understood, (4) lifting or carrying 10 lbs., (5) walking a quarter of a mile without resting, or

(6) climbing a flight of stairs without resting. Difficulty in performing any of these functional activities is classified as a functional limitation in the SIPP.

The **NHIS-D** asked respondents about their ability to perform the following activities: (1) lift 10 pounds, (2) walk up 10 steps without resting, (3) walk a quarter of a mile, (4) stand for approximately 20 minutes, (5) bend down from a standing position, (6) reach up over the head or reach out, (7) use fingers to grasp or handle something and (8) hold a pen or pencil. Inability to perform any of these activities is classified as a functional limitation.

Functional disability: The concept of functional disability was added to the **Decennial Census** in 1990, with a question about whether a person had a health condition that limited his or her ability to go outside the home alone or caused difficulty in taking care of personal needs such as bathing, dressing, or getting around inside the home. The question bears similarities to the **SIPP** concepts of **functional activity** and **activities of daily living**, but is not exactly equivalent.

On the **NHIS-D**, functional disability includes: (1) limitations in or inability to perform a variety of physical activities; (2) serious sensory impairment; (3) serious symptoms of mental illness that severely interfered with life for the past year; (4) long-term care needs; (5) use of selected assistive devices; (6) developmental delays; (7) for children under age 5, inability to perform age-appropriate functions.

Functional limitation(s): See **functional activities.**

IADL: See **Instrumental activities of daily living (IADLs).**

IDEA: IDEA stands for the Individuals with Disabilities Education Act, Part B Program. IDEA is now the major federal program that provides states with financial assistance to educate children and youth with disabilities. Before 1995, **special education** was also funded under **ESEA.**

Instrumental activities of daily living (IADLs): The **NHIS** collects information on people's needs for assistance from others in performing instrumental activities of daily living. The IADLs include: "doing everyday household chores, necessary business, shopping or getting around for other purposes." People who need assistance in **activities of daily living (ADLs)** were not asked about IADL.

On the **SIPP**, instrumental activities of daily living include: going outside the home, keeping track of money or bills, preparing meals, doing light housework, and using the telephone.

(See also **activities of daily living**.)

Life expectancy: Life expectancy is an estimate of the average number of years of life remaining to a person at a particular age, based on a set of age-specific death rates, usually the mortality conditions existing at the time of the estimate.

Labor force: As used by the Bureau of the Census in the March Supplement of the **Current Population Survey (CPS),** the labor force includes people employed as civilians, currently unemployed, or in the Armed Forces during the survey week. People who are neither employed nor seeking employment are not included in the labor force (such as people engaged in housework, attending school, unable to work because of long-term physical or mental illness, people who are retired or too old to work, seasonal workers in an off season, and voluntarily idle people).

Labor force participation rate (LFPR): The LFPR, which is the number of people in a given population that are in the **labor force** divided by the number of people in that population, is a primary measure in labor market analysis.

Major activity: In **NHIS**, people are classified in terms of the major activity usually associated with their particular age group. The major activities for the age groups are (1) ordinary play for children under 5 years of age, (2) attending school for those 5-17 years of age, (3) working or keeping house for people 18-69 years of age, and (4) the capacity for independent living (the ability to take care of personal needs such as eating and dressing, without the help of another person) for those 70 and over. People ages 18-69 years who are classified as keeping house are also classified according to their ability to work at a job or business. (See **activity limitation.**)

Medical expenditures: The **National Medical Expenditure Survey** measures costs for medical care by totaling costs for hospital care, physician services, emergency room, dental services, vision aids, prescription drugs, medical equipment and home care.

Mental disorder: In the **Epidemiological Catchment Area (ECA)** studies, the presence of a mental disorder was determined by asking about a person's symptoms, using the Diagnostic Interview Survey (DIS). People whose symptoms met the criteria for diagnosis based on the American Psychiatric Association's **Diagnostic and Statistical Manual (DSM-III or DSM-IIIR**) were classified as having a mental disorder. (See also **severe mental disorder**.)

NCS: See **National Comorbidity Survey** in Appendix for survey description.

NHIS: See **National Health Interview Survey** in Appendix for survey description.

NHIS-D: See **National Health Interview Survey** in Appendix for survey description.

NHIS-MH: See **National Health Interview Survey** in Appendix for survey description.

NMES: See **National Medical Expenditures Survey** in Appendix for survey description.

National Alliance for Caregiving Survey: See Appendix for survey description.

National Comorbidity Survey: See Appendix for survey description.

National Health Interview Survey (NHIS): See Appendix for survey description.

National Health Interview Survey on Disability (NHIS-D): See **National Health Interview Survey** in Appendix for survey description.

National Health Interview Survey, Mental Health Supplement (NHIS-MH): See **National Health Interview Survey** in Appendix for survey description.

National Medical Expenditures Survey (NMES): See Appendix for survey description.

National Nursing Home Survey: See Appendix for survey description.

Non-institutionalized: Many estimates from federal surveys are based only on people who are not in institutions at the time of the survey, that is, the non-institutionalized people in the population. Institutions include correctional institutions, mental (psychiatric) hospitals, residential treatment centers, tuberculosis hospitals, chronic disease hospitals, homes for the aged, homes and schools for the mentally handicapped, homes and schools for the physically handicapped, homes for unwed mothers, homes for dependent and neglected children, training schools for juvenile delinquents, and detention homes for juveniles.

Non-severe disability: In the **SIPP**, people are classified as having a non-severe disability if they meet the criteria for **disability**, but do not meet the criteria for **severe disability**. For example, a person who has difficulties with **activities of daily living** (one of the criteria for disability) but who does not need **personal assistance** with activities of daily living, would be classified as having a non-severe disability (unless that person met other criteria for severe disability).

OASDI: See Old Age, Survivors, and Disability Insurance.

Old Age, Survivors and Disability Insurance (OASDI): This federally-administered program provides monthly benefits to retired and disabled workers and their dependents and survivors. Benefits are earned in employment covered under Social Security. The part of OASDI that provides benefits to workers on the basis on disability is called **Social Security Disability Income (SSDI)**.

Perceived disability: In the **NHIS-D**, people were asked if they considered themselves to have a disability or are considered by others to have one. This reflects the definition of disability used in the Americans with Disabilities Act (ADA).

Personal assistance: In the **NHIS** core questionnaire, respondents are asked if they "need the help of other people" with personal care needs (**activities of daily living**) or handling other routine needs (**instrumental activities of daily living**). Those who answer affirmatively are categorized as needing personal assistance.

On the **SIPP**, respondents are first asked whether they have difficulty with any activities of daily living or instrumental activities of daily living. If they report difficulties, they are then asked a follow-up question about whether they need the help of another person to perform the activity, that is, the need for personal assistance.

Poverty: Poverty statistics presented in this report are based on a definition of poverty that was originally developed by the Social Security Administration and was linked to the cost of food. The poverty index is based on income thresholds that vary by family size and composition, and the thresholds rise each year by the same percentage as the Consumer Price Index. For example, the average poverty threshold for a family of four was $14,335 in 1992, and $15,141 in 1994.

Prevalence: Prevalence is the number of cases of a disease, number of infected people, or number of people with a given attribute present during a particular interval of time. It is often expressed as a rate or percentage (for example, the prevalence of arthritis per 100 people during a year).

Psychiatric disorder: In the **National Comorbidity Survey**, respondents were interviewed about symptoms, using a structured diagnostic interview. Respondents whose symptoms met the criteria for a mental disorder as defined in the American Psychiatric Association's **Diagnostic and Statistical Manual**, Revised Third Edition (DSM-III-R) were classified as having a psychiatric disorder.

Rehabilitation Services Administration Program Data: See Appendix for description of data source.

Restricted-activity days: From the **NHIS**, a day when a person cuts down on his or her activities for more than half a day because of illness or injury. Include **bed-disability, work-loss** and **school-loss days**.

Rochester Epidemiology Project: See Appendix for description of data source.

SIPP: See **Survey of Income and Program Participation** in the Appendix for survey description.

School-loss days: From the **NHIS**, a day when a child loses more than half a school day because of illness or injury. School-loss days are computed for children 5-17 years of age.

Severe activity limitation: In the **NHIS**, a person who is "unable to carry on" his or her **major activity** is said to have a severe activity limitation.

Severe disability: Severe disability is defined by the **SIPP** as follows: People 15 and over were identified as having a severe disability if they (1) were unable to perform one or more functional activities, (2) needed personal assistance with an ADL or IADL, (3) used a wheelchair, (4) were a long-term user of a cane, crutches, or a walker, (5) had a developmental disability or Alzheimer's disease, (6) were unable to do housework, (7) were receiving federal disability benefits, or (8) were 16 to 67 years old and unable to work at a job or business.

Serious mental illness (SMI): In the 1989 Mental Health Supplement to the **National Health Interview Survey (NHIS-MH),** serious mental illness was defined as having one or more psychiatric disorders in the past year that interfered seriously with one or more aspects of daily life. Household respondents were asked whether anyone in the household had one of a number of psychiatric disabilities, which were listed by name. This type of question differs from a survey like the **Epidemiological Catchment Area (ECA) Survey** and the **National Comorbidity Survey**, in which clinical interviews about symptoms were conducted to determine prevalence of mental disorders.

Severe mental disorder: In the **Epidemiological Catchment Area (ECA)** studies, subjects were interviewed using the Diagnostic Interview Survey and classified as having a severe mental disorder if their symptoms met the criteria for a particular set of **Diagnostic and Statistical Manual** (DSMIII) mental disorders and markedly interfered with social, occupational, and or school functioning. The diagnoses that are considered severe include schizophrenia and related disorders, manic-depressive (bipolar) disorder, autism and related disorders, and severe forms of major depression, panic disorder and obsessive compulsive disorder.

Severe work disability: The **Current Population Survey (CPS)** classified people as having a severe work disability if they (1) did not work in the survey week because of a long-term physical or mental illness that prevents the performance of any kind of work, (2) did not work at all in the previous year because of illness or disability, (3) were under 65 years of age and covered by Medicare, or (4) were under 65 years of age and a recipient of **Supplemental Security Income (SSI)**. (See also **work disability**.)

Special education: Special education refers to free and appropriate public education and related services provided for children and youth with disabilities from birth through age 21. Funding is provided via federal legislation IDEA, part B and, through 1995, by Chapter 1 of ESEA (SOP). (See also **IDEA** and **ESEA**.)

Social Security benefits: Social security benefits for individuals with disabilities include: (1) **Social Security Disability Insurance (SSDI)** which is a part of **the Old Age, Survivors and Disability Insurance (OASDI)** and (2) **Supplemental Security Income (SSI).** Individuals may receive benefits from either or both programs, depending on their work history, age, and financial resources. See individual listings under these terms for more information about each program.

Social Security Disability Insurance (SSDI): A federal program in the Social Security Administration providing monthly benefits to **disabled workers** and their dependents. A person builds protection through employment covered under Social Security (compulsory tax on earnings). The disability definition is an inability to engage in substantial gainful activity because of any medically determinable permanent physical or mental impairment. Later amendments made the disability length of time necessary for eligibility to be at least five months.

Social Security Program Data: See Appendix for description of data source.

Supplemental Security Income (SSI): The federally-administered Supplemental Security Income program provides income support to people 65 and over, blind or disabled adults and blind or disabled children who have little or no income or other financial resources. In order to be considered disabled for SSI, an adult must be unable to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment that is expected to result in death or last for a continuous period of at least 12 months. Blindness is defined as 20/200 or less vision in the better eye with the use of correcting lenses, or with tunnel vision of 20 degrees or less. Children who have a physical or mental impairment which results in marked or severe functional limitations are eligible for SSI.

Survey of Program and Income Participation (SIPP): See Appendix for survey description.

U.S. Department of Education, Office of Special Education, Data Analysis System: See Appendix for description of data source.

Vocational Rehabilitation: This term refers to programs conducted by state Vocational Rehabilitation agencies operating under the Rehabilitation Act of 1973. Vocational Rehabilitation programs provide or arrange for a wide array of training, educational, medical, and other services individualized to the needs of people with disabilities. The services are intended to help people with disabilities acquire, reacquire, and maintain gainful employment. Most of the funding is provided by the federal government.

With employment outcome: The successful placement of a **Vocational Rehabilitation** client into competitive, sheltered, or self-employment for a minimum of 60 days after the completion of all necessary rehabilitation services. This category, "with employment outcome," was formerly called "rehabilitated."

Work disability: People were classified as having a work disability by the **Current Population Survey (CPS)** if they met any of the following criteria: (1) had a health problem or disability which prevents them from working or which limits the kind or amount of work they can do, (2) had a service connected disability or had ever retired or left a job for health reasons, (3) did not work in survey week because of a long-term physical or mental illness or disability which prevents the performance of any kind of work, (4) did not work at all in the past 12 months because of illness or disability, (5) under 65 years of age and covered by Medicare, or (6) under 65 years of age and a recipient of **Supplemental Security Income (SSI)** or **Social Security Disability Insurance (SSDI),** or (7) received veteran's disability compensation. (See also **severe work disability.**)

On the **NHIS-D**, work disability is defined as a limitation in or inability to work as a result of a physical, mental or emotional health condition.

Work limitation: On the **NHIS**, this category includes respondents with a chronic health condition that prevents the performance of work at all, allows only certain types of work to be performed or prevents regular working.

Work-loss days: From the **NHIS**, a day during which a person lost more than half a workday because of illness or injury. Work-loss days are computed for people 18 years and over, in the currently employed population (defined as those who were working or had a job or business from which they were not on layoff during the 2-week period preceding the week of interview).

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Website Addresses

Website addresses are subject to change. The websites listed in this chartbook are current at the time of this document's preparation. This publication, **Chartbook on Women and Disability in the United States**, is also available on the InfoUse website, which will be updated periodically:

http://www.infouse.com/disabilitydata/

Berkeley Planning Associates:
http://www.bpacal.com/biblio.html

Bureau of the Census:
CPS: http://www.census.gov/hhes/www/disable/cps
SIPP: http://www.census.gov/hhes/www/disable/sipp

Center on Emergent Disabilities:
http://www.uic.edu/depts/idhd/ced/

Center for Research on Women with Disabilities:
http://www.bcm.tmc.edu/crowd/

Centers for Disease Control and Prevention (CDC):
Division of Child Development, Disability and Health Homepage
http://www.cdc.gov/nceh/programs/disabil/home.htm
National Center for Health Statistics Homepage
http://www.cdc.gov/nchswww/

Disability Statistics Research and Training Center (University of California, San Francisco):
http://www.dsc.ucsf.edu

National Center for the Dissemination of Disability Research:
http://www.ncddr.org

National Center for Education Statistics:
http://www.nces.ed.gov/nces/pubs/ce/index.html

National Comorbidity Survey:
http://www.hcp.med.harvard.edu/ncs/index.htm

National Institute on Disability and Rehabilitation Research:
http://www.ed.gov/offices/OSERS/NIDRR

National Resource Center for Parents with Disabilities at Through the Looking Glass:
http://www.lookingglass.org

Office of Special Education:
http://www.ed.gov/offices/OSERS/OSEP/index.html

Social Security Administration:
http://www.ssa.gov/statistics/ores_home.html

Appendix

This appendix provides information on the sources of data used in this publication, and the limitations of each source. The major surveys used in this publication are the Survey of Income and Program Participation (SIPP), the National Health Interview Survey (NHIS), which includes the Disability and Mental Health Supplements, the Current Population Survey (CPS), and the Decennial Census. These surveys provide the most comprehensive, current estimates from large, nationally-representative samples. They are presented first in this appendix.

For other topics in the area of women and disability, smaller or more specialized surveys and databases provide invaluable information. Other surveys and databases used in this publication include, in alphabetical order: the Epidemiological Catchment Area (ECA) Survey, the National Alliance for Caregiving Survey, the National Comorbidity Survey (NCS), the National Medical Expenditures Survey (NMES), the National Study of Women with Physical Disabilities, the National Nursing Home Survey, Rehabilitation Services Administration Program Data, the Rochester Epidemiology Project, Social Security Administration Program Data, and the U.S. Department of Education, Office of Special Education, Data Analysis System.

The following summaries describe the surveys, their sampling formats, the size of the respondent bases, and definitions of terms used in the surveys, including how disability is measured. Information is also presented on databases that served as data sources for this publication. More details can be found in the original publications.

The Survey of Income and Program Participation (SIPP) is a multi-panel, longitudinal survey conducted by the U.S. Census Bureau. The SIPP covers the civilian, **non-institutionalized** population of residents living in the United States, and collects data on source and amount of income, labor force information, program participation and eligibility data, and general demographic characteristics. The SIPP also includes disability supplements that ask questions to determine individuals' disability status. Historical background and more detailed information on the SIPP can be found on the Internet at <http://www.sipp.census.gov/sipp>.

Survey design and sampling -- The data in this publication are based on a number of overlapping waves and panels of the SIPP. The survey design is a continuous series of national panels in which the same households are interviewed every four months for periods ranging from 2 1/2 to 4 years. A cycle of four interviews covering the entire sample and using the same questionnaire

is called a wave. Interviews are conducted by personal visit and by follow-up telephone calls. All household members who are 15 years and older are interviewed, if possible, and proxy response is permitted when individuals are not available for interviewing.

Respondents -- Sample size ranged from approximately 34,000-40,000 households per data file. (The 1991-92 and 1994-95 SIPP analyses each constitute a data file.) A rough estimate of the number of individuals interviewed per file would be 85,000 to 100,000, based on an estimated average of 2.5 individuals per household.

Definitions -- The questions that have been asked in the disability supplements of the SIPP were designed to be consistent with the definition of disability set forth in the Americans with Disabilities Act (ADA). People 15 years of age and older were considered to have a **disability** if they met the following criteria:

1. used a wheelchair or had used a cane, crutches or walker for 6 months or longer;
2. had difficulty performing one or more **functional activities**, such as seeing, hearing, speaking, walking, lifting or carrying 10 pounds, or climbing stairs;
3. had difficulty with one or more **activities of daily living (ADLs),** which include getting around inside the home, getting in and out of bed or a chair, bathing, dressing, eating or toileting;
4. had difficulty with one or more **instrumental activities of daily living (IADLs),** which include going outside the home, keeping track of money or bills, preparing meals, doing light housework or using the telephone;
5. was identified as having a developmental disability or a mental or emotional disability;
6. was 16 years or older and had a condition that made it difficult to do housework;
7. was between 16 and 67 years of age and had a condition that limited the amount or kind of work at a job;
8. was under 21 years and received developmental services or had limitations in usual activities such as schoolwork;
9. was under age 65 and covered by Medicare or received SSI.

Functional limitations are defined from the questions asked about the difficulty in performing basic activities such as seeing, hearing, having one's speech understood, walking, carrying or lifting 10 pounds or walking up a flight of stairs. **Activities of daily living (ADLs)** covered in the survey include getting around inside the home, getting in and out of bed or a chair, bathing, dressing, eating and toileting. **Instrumental activities of daily living (IADLs)** covered in the survey

include going outside the home, keeping track of money or bills, preparing meals, doing light housework and using the telephone.

The National Health Interview Survey (NHIS) is a principal source of information on the health of the civilian **non-institutionalized** population of the United States. It has been conducted annually by the National Center for Health Statistics (NCHS) since 1957. Each year, the survey consists of a basic set of questions on health, socioeconomic and demographic items as well as one or more special questionnaires to obtain more detailed information on major current health issues. A special questionnaire on mental health was conducted in 1989 and a special questionnaire on disability, the NHIS-D, was conducted in 1994-95. (See below for a description of these surveys.) The NHIS also provides information about activity limitations and chronic conditions.

Survey design and sampling -- The NHIS is conducted according to a multistage probability design, permitting continuous sampling of the civilian non-institutionalized population living in the United States. Each weekly sample is representative of the target population and is additive with other weekly samples. Sampling is done throughout the year, preventing seasonal bias. Information is obtained about health and other characteristics of each member of the household. The usual sample size is approximately 48,000 households or about 122,000 individuals each year.

Respondents -- The interviewed sample for 1994 was 116,179 individuals (45,705 households) and for 1995 was 102,467 individuals (39,239 households). Response rates were 94.1 percent in 1994, and 93.8% in 1995.

Definitions -- The NHIS defines **chronic condition** as one that has lasted for three months or more, or one that is on the NCHS list of chronic conditions regardless of onset. **Disability** refers to the state of being limited, due to a chronic mental or physical health condition, in the type or amount of activities. The NHIS has three measures of disability: (1) **activity limitation** in **major activity,** (2) **work limitation**, and (3) need for personal assistance with **activities of daily living (ADLs)**.

National Health Interview Survey Supplement on Mental Health (NHIS-MH): In 1989, a special supplement on mental health was included as part of the NHIS. The purposes of the supplement were to update previous estimates of the prevalence of serious mental illness and to examine the use of mental health services and disability program participation of the population with serious mental illness. Information was collected on 113,231 people, a response rate of 96.8% of those who were interviewed on the basic NHIS questionnaire that year or 91.9% of the total NHIS sample for the year. Given that mental illness often carries great stigma and that the survey was not designed to diagnose mental

disorders, the data from this survey are likely to underestimate the actual prevalence of mental disorders.

National Health Interview Survey on Disability (NHIS-D): In 1994-95, a special questionnaire on disability, the NHIS-D, was included as a topical module on the National Health Interview Survey. The survey was conducted in two phases. Phase I of the NHIS-D was designed to identify a wide range of children and adults with chronic conditions, impairments, disabilities and elevated service needs. Information was collected on 107,469 individuals, of whom 30,032 were children. The response rate for the NHIS-D, Phase I, was 87%. Phase II of the NHIS-D was designed as a follow-up questionnaire with individuals who were identified in Phase I. Data from Phase II is not yet generally available. See **functional activity** and **functional disability** in the Glossary for definitions of those terms as used in the NHIS-D.

The Current Population Survey (CPS) is a monthly survey conducted by the U.S. Census Bureau that collects labor force data on the **non-institutionalized** civilian population. The data presented in this publication are from the March Income Supplement, in which questions related to labor force participation and income are asked of all members of the household 16 years of age and older.

Survey design and sampling -- The sample of approximately 60,000 is selected to be representative of the entire population of the United States, and numbers are "weighted" or adjusted to independent population estimates based on the results of the decennial Census. These weights take into account age, gender, sex, race, Hispanic origin and state of residence.

Respondents -- About 60,000 households were eligible to participate in the survey, representing about 1 in every 1,600 households in the country.

Definitions -- Work disability is the only disability measured by the CPS. People are classified as having a work disability if they:

1. have a health problem or disability which prevents them from working or limits the kind or amount of work they can do; or
2. ever retired or left a job for health reasons; or
3. did not work in the survey week because of long-term physical or mental illness or disability that prevents the performance of any kind of work; or
4. did not work at all in previous year because of illness or disability; or
5. are under 65 years of age and are covered by Medicare; or
6. are under 65 years of age and a recipient of Supplemental Security Income (SSI); or
7. received veteran's disability compensation.

The Decennial Census ("The Census") has been conducted every 10 years since 1790. Data in this publication are based on the 1990 census. The Census seeks to simultaneously enumerate all individuals in the United States. Census forms are mailed out and interviewers dispatched to residential addresses, and the Census questionnaire includes questions about both the condition of the housing unit and its occupants.

The "short form" of the 1990 Census asked seven population and seven housing questions; it was intended to be completed by all households (100% sample). The "long form" of the Census contained all of the short form questions and many other questions and was distributed to a sample of the United States population. Questions about disability are contained in the long form of the Census. Data from the decennial Census are used to weight the sample results of the SIPP and the CPS on age, sex, race, and Hispanic/non-Hispanic categories.

Survey design and sampling -- The short form of the decennial Census, which is used to weight other surveys, does not sample from the population, but rather seeks to enumerate the entire population of the United States. About 106 million housing units received the short form. The long form of the Census, which includes disability questions, was distributed to 17.7 million housing units. The Census samples according geographical areas, and smaller, less populated areas are sampled more heavily than densely populated urban areas. The Census also conducts a Post-Enumeration Survey which is used to estimate the degree to which the Census over- or under-counts the population.

Respondents -- The total population count of the 1990 Census was 247.8 million people. Researchers estimate that the Census undercounted the population by 4 - 5.3 million people, based on the results of the Post-Enumeration Survey (Hogan, 1993). The under-count is proportionally larger for certain groups of people (particularly ethnic minorities, and people with low income or low educational level) and for certain geographical areas (Barrett, 1994).

Definitions -- **Disability**, according to the 1990 Census, is defined by answers to the following questions. The **work disability** question is the same as in the 1980 Census. People were asked whether they had a physical, mental or other health condition that limited the amount or kind of work they could do, prevented them from working, or prevented them from using public transportation. In 1990, a new question about **functional disability** asked whether any person in the household had a health condition that limited the ability to go outside the home alone or caused difficulty in taking care of personal needs such as bathing, dressing, or getting around inside the home (Barrett, 1994).

The Epidemiological Catchment Area Survey (ECA) was a multi-site, epidemiological and health services research study that assessed the prevalence and incidence of mental disorders, as well as use of mental health services. There were five sites for the study, and five universities that carried out the research: New Haven, CT (Yale); Baltimore, MD (Johns Hopkins); St. Louis, MO (Washington University); Durham, NC (Duke); and Los Angeles, CA (UCLA).

Survey design and sampling -- Population sizes in the five sites ranged from 270,000 to 420,000 with different mixes of urban, rural and suburban locations as well as ethnic and age compositions. In each area, a probability sample of households was selected, and one adult, age 18 or over, was interviewed about the people in the household. The following groups were oversampled: the elderly in New Haven and Durham, African-Americans in St. Louis, and Hispanic people in Los Angeles.

Respondents -- A total of 18,571 people were interviewed, with a range of 3,004 to 5,034 completed interviews at each site.

Definitions -- The ECA diagnosed **mental disorders** according to the diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders – Third Edition (DSM-III) of the American Psychological Association.

The National Alliance for Caregiving Survey was designed as a telephone survey and conducted between August and September of 1996. A total of 1,509 English-speaking family caregivers participated in interviews. Samples were generated by randomly calling U.S. households to identify caregivers. Blacks, Hispanics and Asian caregivers were oversampled to ensure representation proportional to the ethnic mix in U.S. telephone households. Given the relatively small sample size, there may be limitations to generalizing to the U.S. population. Further information on the survey and sampling issues is available in the report of the National Alliance for Caregiving (1997).

National Comorbidity Survey (NCS): Mandated by Congress and conducted in 1990-92, the NCS was the first survey to administer a structured psychiatric interview to a nationally representative sample. The survey was designed to study the prevalence and correlates of **psychiatric disorders** and the use of services by people with those disorders. The study also focused on the **comorbidity** of substance use disorders and non-substance psychiatric disorders.

Survey design, sampling , and respondents -- A household survey of over 8,000 respondents, ages 15 to 54 years, was conducted in 48 states, based on a stratified, multistage probability sample. The study also included other supplemental samples.

Definitions -- Psychiatric diagnoses were assigned based on a structured psychiatric interview (a modified version of the Composite International Diagnostic Interview, which provides diagnoses according to the Diagnostic and Statistical Manual of Mental Disorders – Third Edition, Revised, DSM-III-R, of the American Psychological Association). The study did not measure disability, but rather the presence or absence of psychiatric disorders.

The National Hospital Discharge Survey (NHDS) is a continuing nationwide survey of hospitals, focusing on short-stays rather than long-term care. On the basis of patient records, the survey estimates the causes of illness and injury nationwide.

Survey design and sampling -- Hospitals are selected to have patient records abstracted and analyzed. The survey uses a stratified sampling methodology, based on hospital size, number of discharges, primary diagnoses, patient age and gender group, and other factors. Statistical adjustments are made for non-responding hospitals and missing abstracts.

Respondents -- In 1995, 525 hospitals were selected, 512 met the inclusion criteria, 466 participated, and 263,000 medical records were abstracted.

Definitions -- Among other purposes, the survey provides national estimates on causes of short-term disabilities that result from illness and injury.

The National Medical Expenditures Survey (NMES) is a national probability sample of households done for the Agency for Health Care Policy and Research (AHCPR). It surveyed the civilian, **non-institutionalized** population of the United States, as well as medical providers, about medical service use and expenditures, sources of payments for health care, and health insurance coverage. It measured disability at two levels: **activity limitations** and **activities of daily living (ADL)** limitations.

Sampling -- The NMES has a stratified multistage area probability sample design. The survey oversamples for poor and low-income families, elderly people, individuals with functional limitations, Blacks, and Hispanics. Participants were interviewed five times between February 1987 and July 1988.

Respondents -- A screening interview was conducted in 35,600 households. The resulting sample consists of approximately 35,000 people in 14,000 households.

Definitions -- **Activity limitation** is defined by age group. Adults 18 years and over are considered to have an activity limitation if they answer positively to

either of the following questions: 1) Does your health keep you from working at a job, doing work around the house, or going to school? and 2) Are you unable to do certain kinds or amounts of work, housework, or school work because of your health? For school-aged children between the ages of 5 and 17, activity limitations are defined by questions about attending or needing special schools or classes, and limitations in school or other activities because of an impairment or health problem. For young children under 5 years, activity limitation is defined by questions about limitation in play or other activities, due to an impairment or health problem.

National Nursing Home Survey (NNHS): The National Center for Health Statistics has conducted four national nursing home surveys, beginning in 1973. The estimates in this publication of the number of elderly people in nursing homes were based on the results of the most recent (1995) NNHS.

Sampling -- The 1995 survey sampled only nursing homes that provided some level of nursing care, excluding homes that provided only personal care or housing. The sample of 1,500 homes was selected from a sampling frame of 17,500 nursing homes contained in the National Health Provider Inventory.

Respondents -- Information on 8,000 current residents was obtained from approximately 1,400 responding nursing homes. Staff members who were familiar with resident care completed forms, and information was also abstracted from medical records.

Definitions -- For the purpose of this publication, the survey provided estimates of the number of elderly people living in nursing homes.

The National Study of Women with Physical Disabilities was a mail survey of 860 women, 439 with physical disabilities and 421 without physical disabilities. Participants with disabilities were between the ages of 18 and 65 years, had a self-reported physical disability resulting in functional limitations and had no known cognitive impairments, mental health problems or difficulty reading English. They were recruited through independent living centers and announcements in disability publications. These women gave parallel questionnaires (minus the disability questions) to non-disabled friends, so that comparisons could be made between women with and without disabilities. Although the survey was not designed to be nationally representative, it is the first study to survey a relatively large number of women with and without disabilities about their experiences with abuse.

Rehabilitation Services Administration Program Data is collected by the Rehabilitation Services Administration (RSA) from all the states and compiled annually. Information used in this chartbook was made available by RSA from unpublished data analyses.

The Rochester Epidemiology Project (REP) is not a survey but rather an archive of medical records that has been kept since 1907 at the Mayo Clinic in Rochester, MN. This population-based medical database is particularly useful for studying the incidence and prevalence of diseases over relatively long periods of time and for studying the relationships among different diseases. The archives are also helpful in comparing costs of medical treatment for people with a given disease, compared to people who do not have that disease. The REP currently supports nearly 1,000 research projects and provides data to hundreds of other studies each year.

Social Security Administration Program Data is collected by the Social Security Administration(SSA) and published each year in the Annual Statistical Supplement to the Social Security Bulletin. A substantial number of the tables in this publication are based on sampling 1-percent or 10-percent of the files from the administrative records. Due to sampling error, some of these estimates may be different from the results that would have been obtained if all the records had been used. Detailed information on sampling variability may be obtained in the Annual Supplement. [See also the Glossary for definitions of the following terms that are used in the Social Security Administration Program Data: **Disabled worker; Old Age, Survivors and Disability Insurance (OASDI); Social Security benefits; Social Security Disability Insurance (SSDI)**; and **Supplemental Security Income (SSI).**]

U.S. Department of Education, Office of Special Education, Data Analysis System: This data system is the source of program data on special education in the United States. Data is collected from all the states on children and youth, ages 0 to 21 years, who are served under **IDEA**, the Individuals with Disabilities Education Act. Analyses of these program data are published each year in an annual report to Congress; the Twentieth Annual Report (U.S. Department of Education, Office of Special Education and Rehabilitation, 1998) is the most recent such report. Program data are also published annually in the Condition of Education (U.S. Department of Education, National Center for Educational Statistics, 1997, 1998).

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